Debra A. Harley · Noel A. Ysasi
Malachy L. Bishop · Allison R. Fleming *Editors*

Disability and Vocational Rehabilitation in Rural Settings

Challenges to Service Delivery

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Editors
Debra A. Harley
Department of Early Childhood, Special
Education, and Rehabilitation Counseling
University of Kentucky
Lexington, KY, USA

Malachy L. Bishop
Department of Early Childhood, Special
Education, and Rehabilitation Counseling
University of Kentucky
Lexington, KY, USA

Noel A. Ysasi
College of Health and Human Services
Rehabilitation Services and
Rehabilitation Counseling
Northern Illinois University
DeKalb, IL, USA

Allison R. Fleming
Pennsylvania State University
Rehabilitation and Human Services
University Park, PA, USA

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Foreword

Disability and Vocational Rehabilitation in Rural Settings is an exceptionally timely, unique, and comprehensive body of work that was created to ultimately help persons with disabilities and their family members living in underserved and rural geographic areas of the United States as well as internationally. This text brings renewed interest to the complex interplay of the unique cultural differences that challenge persons with disabilities who are disadvantaged on so many different levels politically and economically, especially in mental and physical healthcare, accessibility to services, and government entitlement programs that assist individuals and families transitioning in and out of poverty. Counselor educators and researchers, preprofessional rehabilitation counselors, and others in the related counseling professions will easily recognize this material as a highly respected body of work. Clearly, this text has been handcrafted by a group of expert authors that have a unique point of view to offer the rehabilitation counseling and related counseling professions.

Indeed, this text brings new meaning to older constructs such as the "war on poverty" and "health disparities." This authoritative source enhances the renewed interest in the complex interplay of issues related to poverty and how this cycle involves multiple dimensions such as social, cultural, familial, and economic. Today, the consequence and impact of poverty on vulnerable populations is far-reaching and multidimensional. Poverty in rural America transcends individuals' mental and physical health conditions, educational and career opportunities, financial stability, and many other life areas which impacts everyone.

One of the unique aspects this comprehensive body of work offers is the careful attention given to the widespread problem of poverty in vulnerable populations, within different cultural groups in the United States as well as internationally. Moreover, this work extends beyond a "statement of the problem" approach. It offers guidelines and solutions for increasing coping and resiliency skills, capacity building, and educational training approaches that have shown to positively impact rural communities and groups of individuals with disabilities.

The effects of poverty are most harmful to those most vulnerable which overpoweringly include children, older adults, and people with disabilities. The condition of poverty is particularly worrisome for persons with disabilities where almost 22% live in poverty, compared to 13% of those without disabilities. Persons with chronic and persistent health conditions require greater financial support and access to healthcare than those without such financial constraints or healthcare issues. This body of work makes it clear that the implication for living in poverty, particularly in rural and underserved areas geographically, is that one is at risk in so many different life areas. Overall, the devastating consequences of poverty itself may be reflected in poverty of the mind, body, and spirit.

Disability and Vocational Rehabilitation in Rural Settings is extraordinary because it offers much more than a review of the literature and discussion of issues related to poverty and social justice. Such limited constructs do not translate well into our twenty-first-century political and economic environments. Thus, readers will find that the material is comprehensive in nature, practical, and particularly functional for counselor educators, researchers, practitioners, as well as preprofessional counselors in the helping professions. It offers a very close, up-front, personal, and experiential account of the problems and solutions for rehabilitation counselors and other related helping professions providing services to persons with disabilities in rural settings. The expert authors who embody this work understand the critical mass that impacts persons in poverty from the medical, physical, vocational, psychosocial, emotional, spiritual, and cultural perspective.

One of the most valuable lessons offered in *Disability and Vocational Rehabilitation in Rural Settings* highlights the delicate balance of providing services that are both culturally sensitive and culturally appropriate yet can be offered within the boundaries of certain governmental programs and policies that determine eligibility and assistance. The chapters in this unique work provide an in-depth discussion that can be used as a primary resource to educate, inform, and advocate reality-based, solution-focused, and culturally relevant approaches rooted in cultural empathy.

I started my own career at a community-based rehabilitation center (sheltered workshop) around 1979 in Murphysboro, IL, a small rural town in Southern Illinois close to the border of Kentucky and Missouri. Besides doing work adjustment training, job placement activities, and job coaching with these clients, I also drove the bus to pick them up for work in the morning and drop them off at the end of the day. I really got to know their family members and the psychosocial challenges of individuals with mental and physical disabilities living in rural America. This was my introduction to working with people who had a variety of medical, physical, developmental, neurocognitive, psychiatric, and chronic health conditions that were disabling. I remembered this as a very rewarding opportunity that helped launch my career, which has spanned over 30 years. Metaphorically, driving the "short bus" placed me in the position of leadership, guiding people to find their way through work, education, and career opportunities and then independent or support living arrangements. I have learned some valuable lessons living and working in this small rural community because it reflected the content in this volume. This work provides a valuable resource to the reader that reflects my own experiences working with "salt-of-the-earth" people who have come from humble beginnings.

Overall, I found *Disability and Vocational Rehabilitation in Rural Settings* to be well written, organized in a clear and concise manner, and presented in a well-informed and balanced way. This is a valuable resource for counselor educators, researchers, and preprofessional counselors alike. It is an authoritative resource for practitioners who care about serving persons with disabilities and others vulnerable to the conditions and experiences of poverty.

Mark A. Stebnicki

Professor and Coordinator of the Military
and Trauma Counseling Program,
Department of Addictions and Counseling
College of Allied Health Sciences
East Carolina University
Greenville, NC, USA

Preface

As editors of this book, Noel, Malachy, Allison, and I have over 45 years of combined experience in education, research, and service delivery in rehabilitation, disability, social justice, and social services. As faculty members in rehabilitation counseling education programs, we were looking for a book on rural rehabilitation and discovered a 1999 edition as the most current. The United States and other countries are nations of primarily rural landmass; therefore, understanding the challenges of rural residents with disabilities in these regions is important in service delivery, education and training, research, and funding and policy development. In addition to areas in which the terms rural, frontier, territory, and remote regions are identified specifically in chapters, throughout this book, the term rural is used as an umbrella term that is inclusive of all others. Our goal for this book is to discuss both challenges and strengths of rural life. We acknowledge the diversity and complexity of rural regions, but they share some common characteristics.

Our 38 chapters cover the following topics pertaining to disabilities in rural communities: economic development; poverty; transportation, accessibility, and accommodation; technology; healthcare; ethical practice and dual relationships; resilience and strengths; military personnel; marginalized racial and ethnic adults and cultural competence and social justice; adolescents and transition students; offender populations; American Indians; agricultural, farm, and immigrant workers; sensory impairments; international perspectives from Africa, Asia-Pacific region, Australasia, Canada, Mexico, India, Turkey, Colombia, and the United Kingdom; multiple sclerosis; substance-related and addictive disorders; Workforce Innovation and Opportunity Act; impact of the Americans with Disabilities Act; forensic vocational rehabilitation; climate and weather; developing personnel through online learning; recruiting and retaining rehabilitation counselors in rural communities; capacity building and collaboration; volunteers and paraprofessionals; and research and evidence-based practices. Our comprehensive text recognizes the challenges faced by vocational rehabilitation, like other human service providers in rural communities, which are well documented.

Our text provides a perspective to rethink the delivery of vocational rehabilitation services in rural areas. A unique feature is that authors of individual chapters represent an array of diverse backgrounds and expertise, including doctoral students in rehabilitation counseling. The inclusion of an international perspective adds to the understanding of globalization of disabilities in rural areas.

We do not present this text as inclusive of all aspects that impact rural communities, but rather, we hope that it will be an important contribution to the existing literature as well as a response to the contextualization of rural rehabilitation service, practice, policy, and research. Our desire is for this text to serve as a practical and reliable resource for those studying and teaching and for those involved in vocational rehabilitation and other human and social service delivery. Similarly, policy and decision-makers, advocates, community leaders, families, and persons with disabilities themselves may benefit from this text.

Lexington, KY, USA	Debra A. Harley
DeKalb, IL, USA	Noel A. Ysasi
Lexington, KY, USA	Malachy L. Bishop
University Park, PA, USA	Allison R. Fleming

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Editors and Contributors

About the Editors

Debra A. Harley, PhD, CRC, LPC is a professor in the Clinical Rehabilitation Counseling in Mental Health Program and co-coordinator of the Rehabilitation Counseling Education, Research, and Policy Doctoral Program at the University of Kentucky. She received her PhD from Southern Illinois University at Carbondale. Dr. Harley has over 23 years of experience in teaching and research. Dr. Harley holds the distinction of Provost's Distinguished Service Professor. She has published over 85 journal articles and 47 book chapters. Dr. Harley is past editor of the *Journal of Applied Rehabilitation Counseling* and the *Journal of Rehabilitation Administration* and guest editor of numerous special issues of rehabilitation journals. She is coeditor of several books including *Contemporary Mental Health Issues Among African Americans* and the *Handbook of LGBT Elders: An Interdisciplinary Approach to Principles, Practices, and Policies*. Dr. Harley is a faculty affiliate with the Department of Gender and Women's Studies, the Center on Research on Violence Against Women, and the Human Development Institute at the University of Kentucky. She is the recipient of the 2006 National Council on Rehabilitation Education Educator of the Year Award and a National Rehabilitation Association Switzer Scholar.

Noel A. Ysasi, PhD, CRC is an assistant professor in the Rehabilitation Services and Rehabilitation Counseling Program at Northern Illinois University. He acquired his PhD from the University of Texas Rio Grande Valley. Dr. Ysasi's professional work experience involves 10 years of teaching in higher education, forensic rehabilitation, working with the veteran population, and has authored and co-authored multiple refereed journal publications and book chapters. Dr. Ysasi has been the recipient of multiple awards, including a Lifetime Achievement Award by the US Department of Veteran Affairs, the 2015 Doctoral Dissertation of the Year by the Foundation of Life Care Planning, and the 2015 National Doctoral Student Awards by the National Council on Rehabilitation Education, and the American Rehabilitation Counseling Association.

Malachy L. Bishop, PhD, CRC is a professor in the Clinical Rehabilitation Counseling in Mental Health Program at the University of Kentucky. He received his PhD from the University of Wisconsin–Madison. Dr. Bishop is the coordinator of the Rehabilitation Counseling Education, Research, and Policy Doctoral Program. He also serves as director of research and development for the Human Development Institute at the University of Kentucky, Kentucky's University Center for Excellence in Developmental Disabilities Education, Research and Service. Dr. Bishop's clinical background includes rehabilitation counseling, rehabilitation psychology and neuropsychology in physical medicine and rehabilitation and other healthcare settings, and vocational assessment. Dr. Bishop has authored over 100 journal articles and book chapters and two books in healthcare and rehabilitation counseling. He conducts research on psychosocial and employment-related aspects of chronic neurological conditions, including epilepsy, multiple sclerosis, and brain injury, quality of life and adaptation to disability, self-management, and developmental disabilities. Dr. Bishop is a five-time recipient of the American Rehabilitation Counseling Association's Research Award and the 2015 recipient of the National Council on Rehabilitation Education Researcher of the Year Award.

Allison R. Fleming, PhD, CRC is an assistant professor in the Rehabilitation and Human Services Program at Pennsylvania State University. She received her PhD from Michigan State University. Dr. Fleming's professional experience includes work as a vocational rehabilitation counselor, a staff trainer for RCEP, and a faculty in rehabilitation counseling at the University of Kentucky. Her research interests include the application of the International Classification of Functioning, Disability and Health to the conceptualization of quality of life among individuals with disability, professional identity in rehabilitation counseling, and post-secondary and employment outcomes for young adults with disabilities.

Contributors

Maram Alfulayyih is a doctoral student in Rehabilitation Counseling Education, Research, and Policy Doctoral Program at the University of Kentucky. She received her master's degree in special education from the University of Texas at San Antonio. Her research interests include, but are not limited to, rehabilitation psychology and rehabilitation counseling of individuals with disabilities.

Marisol Moreno Angarita, PhD is a professor at the National University in Bogotá, Colombia. She is a cofounder of the Master's Program in Disability and Social Inclusion and the Institute for Human Development, Disabilities and Diversity. Dr. Moreno takes a social justice perspective, and her work emphasizes health, educational, and labor services for people with disabilities. She has authored many publications, research studies, and toolkits on topics like early detection of children with delays/disabilities, inclusive education, rehabilitation, and universal design for inclusion.

James Athanasou is a psychologist and associate professor (part-time) in rehabilitation counseling at the University of Sydney. He specializes in personal injury and return to work. He lectures in the area of vocational development and the medical-psychosocial aspects of rehabilitation.

Deniz Aydemir-Döke is a counselor education and supervision PhD candidate at Pennsylvania State University. She had her master's degree in psychological counseling and guidance from Middle East Technical University. Her research interests are well-being of people with disabilities, body image, multicultural counseling, microaggressions, and post-secondary transition of blind youth. She is coeditor of a Turkish disability magazine.

Daniel Balcazar, BA is currently a master's student in the School of Public Health at Emory University in Atlanta. Mr. Balcazar is interested in the health conditions of undocumented Latino immigrants in the United States and social justice efforts to address their healthcare needs.

Fabricio E. Balcazar, PhD is a professor in the Department of Disability and Human Development at the University of Illinois at Chicago. His primary interest is in developing methods for enhancing and facilitating consumer empowerment and personal effectiveness of individuals with disabilities. Dr. Balcazar has published over 70 peer-reviewed journal articles, and he is a fellow of the American Psychological Association (APA). He is also the recent president of Division 27 of the APA, the Society for Community Research and Action.

Molly Baldridge is currently a middle school special education teacher in Lexington, Kentucky. She received her undergraduate degree at the University of Kentucky, where she specialized in teaching students with moderate to severe disabilities. Molly first experienced special education in India during a study abroad trip with the University of Kentucky. Upon return, the needs she had seen while abroad drove her back to India for 4 more months. It was during this time that she worked to train and equip the staff of a small special education school in Southern India on special education. She worked to train the teachers, staff, and some families on behavior management, functional skills, systematic instruction, community awareness, and more.

David T. Beach, PhD, CRC is the director of the Disability Resource Center at the University of Kentucky. Previous to this position, Dr. Beach was the executive director of the Kentucky Office of Vocational Rehabilitation, responsible for the provision of vocational rehabilitation services to more than 25,000 Kentuckians with disabilities. While there, he gained national recognition for his efforts related to the integration of asset development and financial literacy into the public VR program. He has served the profession in many service-related roles, most recently as president of the National Rehabilitation Association.

Walter Bower, PhD is the preservice training coordinator at the Human Development Institute (HDI) at the University of Kentucky. He received a doctoral degree in sociology from the University of Kentucky. He coordinates practicum placements for students in HDI’s Graduate Certificate in Developmental Disabilities Program. He also directs the family mentorship program and serves as the co-chair of the Underserved Populations Engagement Committee. Prior to this position with HDI, he served as the program coordinator for Project CARAT (Coordinating and Assisting the Reuse of Assistive Technology) in the Kentucky Office of Vocational Rehabilitation making assistive technology and durable medical equipment more accessible for individuals with disabilities in Appalachian Kentucky.

Susanne M. Bruyère, PhD, CRC is the director of the Yang Tan Institute and a professor of disability studies. Professor Bruyere is also currently project director and a co-principal investigator of numerous research efforts focused on employment disability nondiscrimination and disability employment policy. She is a past president of the Division of Rehabilitation Psychology (22) of the American Psychological Association, the American Rehabilitation Counseling Association, and the National Council on Rehabilitation Education. She holds a doctoral degree in rehabilitation counseling psychology from the University of Wisconsin–Madison, is a fellow in the American Psychological Association and a member of the National Academy of Social Insurance, and currently serves as an executive board member of the Division of Rehabilitation Psychology (22) of the American Psychological Association; she is also a past chair of GLADNET (the Global Applied Disability Research and Information Network on Employment and Training) and a past chair and current board member of CARF (a rehabilitation facility accreditation organization).

Brenda Cartwright, EdD, CRC, NCC, MHC is a professor of rehabilitation counseling at Winston-Salem State University. Prior to her current position, Dr. Cartwright has held teaching appointments at several universities in the nation and internationally. She received her doctorate in rehabilitation counseling leadership from George Washington University in Washington, DC. She has over 20 years of counseling and administrative experience in state-federal vocational rehabilitation, private rehabilitation, and forensic settings. She serves and provides leadership on national, state, and university levels. Dr. Cartwright has published and presented widely on disability and rehabilitation-related issues, cultural diversity issues, and professional ethics in counseling. She is the recipient of numerous national awards in recognition of scholarly contributions to multiculturalism in the rehabilitation field.

Ashley Craig, PhD is a professor of rehabilitation studies of Sydney Medical School in the University of Sydney. He has been studying the impact of serious injury for many years, focusing on improved psychosocial treatments and factors that influence recovery. He has published over 250 refereed papers, books, and book chapters and won over $10 million in competitive funding in the past 10 years. He is also a senior clinical psychologist, specializing in testing injured people with secondary conditions such as chronic pain, depression, and PTSD.

Ralph M. Crystal, PhD, CRC, LPC is a professor and coordinator of the Clinical Rehabilitation Counseling Program at the University of Kentucky and oversees the campus and distance learning master's degree programs. He developed an online course on rural rehabilitation and has written extensively on rehabilitation issues. Dr. Crystal also maintains a private forensic rehabilitation practice.

Abdoulaye Diallo, PhD, CRC is an assistant professor in the Department of Rehabilitation. He earned his master's degree in professional counseling and in religion from Liberty University and his doctorate in rehabilitation counseling from Michigan State University. His current areas of research interest include attitudes toward persons with disabilities, multicultural counseling, religion/spirituality and health, employment for persons with disabilities, pedagogue, and depression.

Lisa Dunkley, MA is a doctoral student in Rehabilitation Counseling Education, Research, and Policy Doctoral Program at the University of Kentucky. Her research interests include working with adult and juvenile offender populations with disabilities to reintegrate them in society. In addition, Ms. Dunkley has a passion for working with transition age youths with disabilities with career readiness, higher education, independent living, and advocacy. Ms. Dunkley is dedicated to service directed toward improving the lives of people with disabilities across the lifespan.

Eliana Isabel Bedoya Durán, MA is an auxiliary professor of psychology at the "Universidad del Valle" in Cali, Colombia. She is currently a doctoral student at the "Pontificia Universidad Católica de Valparaíso" in Viña del Mar, Chile. Ms. Bedoya has conducted research with populations displaced by the armed conflict in rural Colombia, particularly in the area of economic development and physical and mental health.

Elif Emir-Öksüz received her mental health counseling degree from Xavier University, and she is a doctoral student at the University of Cincinnati in the counselor education program with specialty training in multicultural/social justice counseling. She is also certified on reality therapy. Ms. Emir-Öksüz worked with Dr. Wubbolding during her certification training and translated Dr. Wubbolding's book *Reality Therapy* into Turkish. In addition, she coauthored a book chapter about grief counseling with the current president of the Turkish Counseling Association Dr. Bilge. Ms. Emir-Öksüz has presented and been invited guest on counseling and disability concerns and infusing disability-related training across the counseling curriculum in various platforms both in the United States and Turkey. As a community advocate, she has served as the founding vice president and project manager for Disabled Women Association in Ankara, Turkey, and since 2014 as coeditor and author of *EEEH Dergi*, a Turkish magazine about disability rights, the social and cultural aspects of disability, and related social justice concerns. She serves as a member of the UC Counseling Diversity Work Group and was placed second with her team for the American Counseling Association (ACA) 2016 Graduate Student Ethics Competition. She was a panelist on the ACA international student panel in 2016. Recently, she was selected for the Ohio Counseling Association Emerging Leaders Program for 2016–2017.

William A. Erickson, MS is a researcher at the Yang Tan Institute at Cornell University. He has been actively involved with disability research for over 15 years and has extensive experience in employer research, disability statistics, secondary data sources, survey design, web accessibility, and youth transition-related research. He is also a technical assistance disability statistics expert and has answered thousands of technical assistance requests regarding disability statistics and related information for over 12 years through Cornell University's disabilitystatistics.org and is the lead researcher in the production of the heavily used Annual Disability Status Report series.

Glacia Ethridge, PhD, CRC is an assistant professor in the Mental Health Counseling-Rehabilitation Program at North Carolina Agricultural and Technical State University. She also serves as the program coordinator of the Rehabilitation Counseling and Behavioral Addictions Certificate Program (RCBA). Dr. Ethridge is a certified rehabilitation counselor who has work experience in the public, private, and nonprofit sectors. Her research interests are in the areas of social justice, psychiatric rehabilitation, substance abuse, offenders, school-to-work transition, and career barriers.

Michael Frain, PhD, CRC is a professor of counselor education at Florida Atlantic University in Boca Raton. His research interests include rehabilitation of veterans; rehabilitation counseling issues of persons with HIV/AIDS, brain injury, multiple sclerosis, and other chronic conditions; the needs of families; and the effective training of rehabilitation counselors. Dr. Frain has published 48 articles in peer-reviewed journals and book chapters. His work has been recognized through numerous national awards from organizations such as the American Psychological Association, the American Rehabilitation Counseling Association, and the National Council on Rehabilitation Education. He received his PhD in rehabilitation psychology from the University of Wisconsin–Madison in 2003, after receiving his master's degree in counseling psychology from the University of Missouri in 1994.

Bryan O. Gere, PhD, CRC is an assistant professor of rehabilitation counseling at the Department of Psychology and Counseling of Alabama A&M University, Huntsville, AL. His research interests include fiscal management of the state VR and community rehabilitation programs, HIV/AIDS interventions among rural and underserved populations, vocational rehabilitation of veterans with disabilities, multicultural and diversity issues, and international rehabilitation.

Kayla D. Goodman, BA earned a bachelor of arts degree in psychology from North Carolina Agricultural and Technical State University. Ms. Goodman is continuing her graduate studies at the university in the Mental Health Counseling-Rehabilitation Program as well as pursuing a Certificate in Rehabilitation Counseling and Behavioral Addictions. Her research interests include adolescent African-American males and criminal behavior, inner city youth and trauma, and the effect of children's home environments on mental health.

Sherri L. Greer, MRC is retired from the Kentucky Office of Vocational Rehabilitation where she last served as deputy executive director and long-time director of program services. She is co-instructor for the University of Kentucky Graduate Program in Rehabilitation Counseling and a graduate of this same program.

Shane Heasley is a vocational rehabilitation consultant based in New Zealand's South Island. He completed his undergraduate studies at Otago University and graduate studies with AUT University and Rehabilitation Teaching and Research Unit at Otago University's Wellington School of Medicine and Health Sciences. He is a fellow of the Career Development Association of NZ.

Lucy Wong Hernandez is an instructor in the Department of Counseling, Educational Psychology and Foundations, College of Education, at Mississippi State University (MSU). Mrs. Wong Hernandez served as executive director of Disabled Peoples' International (DPI) from 1996 to 2002. As the executive director of DPI, a nongovernmental organization with consultative status with the United Nations (UN), she dedicated her work to the inclusion of disability issues in the United Nations policy agendas, where she also promoted the protection of human rights, social inclusion, and the equalization of opportunities for all persons with disabilities worldwide.

Elizabeth Hunter, PhD is an assistant professor in the Graduate Center for Gerontology at the University of Kentucky. She received a PhD in gerontology and completed postdoctoral training in cancer prevention and control at the University of Kentucky. Her research interest is in chronic health management, physical function/participation, and health disparities. She is co-principal investigator of the Kentucky AgrAbility Program and is a cofounder of the Kentucky Appalachian Rural Rehabilitation Network (KARRN). She is currently the co-PI of a PCORI Engagement Award focused on people with spinal cord injury, traumatic brain injury, or stroke living in rural Kentucky.

Ronald J. Hustedde, PhD is a professor of community and leadership development at the University of Kentucky. He is also director of the Kentucky Entrepreneurial Coaches Institute, a unique leadership program that builds grassroots entrepreneurial advocates and leaders in rural Kentucky. He is also part of E-Discovery Challenge, an educational program for middle school and high school students in Kentucky's Appalachian communities. Hustedde is past president of the Community Development Society and received his PhD in sociology from the University of Wisconsin–Madison.

Byung Jin Kim, MS is a student in the Rehabilitation Counseling Education, Research, and Policy Doctoral Program at the University of Kentucky. He had two publications accepted during his first year. He received his master's degree in counseling psychology from Handong Global University, South Korea.

Benson Kinyanjui, PhD is a graduate of the Rehabilitation Counseling Education, Research, and Policy Doctoral Program at the University of Kentucky. His research interests include traumatic brain injury, international rehabilitation, and distance learning pedagogy.

Delia R. Kpenosen, BS earned a bachelor of science degree in criminal justice from North Carolina Central University. She is currently a graduate student in the Mental Health Counseling-Rehabilitation Program and pursuing a Certificate in Rehabilitation Counseling and Behavioral Addictions at North Carolina Agricultural and Technical State University. She is an active member of the student Rehabilitation Counseling Association (RCA). Her research interests include behavioral health problems of offenders, ex-offenders, and juveniles and reentry in addition to childhood trauma and its impacts on criminal behavior and correctional counseling.

Erma J. Lawson, RN, MA, PhD is an associate professor at the University of North Texas' Department of Sociology. She earned a doctoral degree in medical sociology from the University of Kentucky. Dr. Lawson's research has explored the relationship between family structure and ill health among African Americans, health disparities, and multicultural health. She has participated in HUD's community/university health partnerships and designed school-based anti-violence programs. She has published in major scholarly journals, including *The Sociology* of *Health and Illness*, the *American Journal of Obstetrics and Gynecology*, the *Journal of Public Health*, *Cancer Nursing*, and *Family Relations*. She is the first author of *Black Men and Divorce* (SAGE Publications). Currently, she is exploring the psychosocial context of race, gender, and heart transplantation through narrative research and teaches courses in health and illness and qualitative research.

Melissa Manninen Luse, PhD, LPC, CRC is an assistant professor and the coordinator for the Online Rehabilitation and Human Services Minor at Pennsylvania State University, in the Rehabilitation and Human Services Program. Dr. Luse is a licensed professional counselor in the state of Michigan and is a certified rehabilitation counselor. Her work/interest includes ethical dilemmas counselors face in rural and small town communities and the development and effectiveness of online counseling programming.

Irmo Marini, PhD, CRC is a professor in the Department of Rehabilitation at the University of Texas Rio Grande Valley. He earned his doctorate in rehabilitation at Auburn University and a master's degree in clinical psychology from Lakehead University in Thunder Bay, Canada. Dr. Marini is former chair of the Commission on Rehabilitation Counselor Certification, former president of the American Rehabilitation Counseling Association, recipient of the 2009 Distinguished Career Award in Education from the National Council on Rehabilitation Education, and the 2010 recipient of the J. F. Garrett Distinguished Career Award in Research from the American Rehabilitation Counseling Association.

Kristin L. Maxwell, PhD, CRC is a clinical assistant professor in the Clinical Rehabilitation Counseling Program at the University of Kentucky (UK), in the Department of Early Childhood, Special Education, and Rehabilitation Counseling. Dr. Maxwell received her PhD from the University of Wisconsin–Madison in 2016. She is currently developing an undergraduate program of study for the Clinical Rehabilitation Counseling Program at the UK.

Bradley W. McDaniels, MRC is a student in the Rehabilitation Counseling Education, Research, and Policy Doctoral Program at the University of Kentucky. During his first year, he had four publications accepted, had three poster presentations at national conferences, and completed two book chapters and one chapter update. He was the 2015 winner of the ExploreVR Open Data Competition through the Institute for Community Inclusion. His research interest includes neurological disorders.

Elias Mpofu, PhD, DEd, CRC, FASORC is a professor of rehabilitation counseling at the University of Sydney. His main research focus is on person-centric rehabilitation support interventions with culturally diverse clients applying the World Health Organization's International Classification of Functioning, Disability and Health. Dr. Mpofu is a fellow of the Australian Society of Rehabilitation Counselors and editor of the *Australian Journal of Rehabilitation Counseling*. In addition, Dr. Mpofu is a distinguished visiting research professor at the University of Johannesburg, South Africa.

Patricia Mundt, MA, CRC is retired from Georgia State University where she was a human resource development specialist for the Regional Rehabilitation Continuing Education Program for Administration and Management. She also worked for the Nevada Division of Rehabilitation for many years. She is currently a co-instructor for the University of Kentucky Graduate Program in Rehabilitation Counseling. She is a graduate of Auburn University with a master of science degree.

Kaylee Ortiz is currently in the Applied Behavior Analysis Graduate Program at the University of Kentucky. She is an assistant in the introduction to special education class. She received her undergraduate degree in learning and behavior disorders at the University of Kentucky in 2016. Kaylee traveled to Southern India in 2014, where she worked with an interdisciplinary team to assess students with disabilities in a small school. She took on the role of special educator and was able to provide suggestions to teachers, parents, and therapists on various educational interventions.

Stacie L. Robertson, PhD, CRC is an associate professor in the Department of Special Education, Rehabilitation, and Counseling (SRC) at California State University, San Bernardino. Dr. Robertson formerly spent nearly 15 years on faculty at Southern Illinois University in the Rehabilitation Institute. She has a PhD in counseling psychology from Pennsylvania State University and an MS in rehabilitation counseling from the University of Illinois and is a certified rehabilitation counselor (CRC). Dr. Robertson has served locally and nationally to enhance services to individuals with disabilities. Her past service works include sitting on the Board of Directors for the Statewide Independent Living Council of Illinois and serving as a commissioner of the Commission on Rehabilitation Counselor Certification.

Jackie Rogers, PhD, CRC is an associate clinical professor and coordinator of the Rehabilitation Counseling Distance Education Program at the University of Kentucky. She completed her doctoral degree in educational psychology with an emphasis in rehabilitation counseling and has a master's degree in rehabilitation counseling. She has over 25 years of experience in both public and private rehabilitation agencies providing direct services to individuals with disabilities.

Christopher Rymond, MRC, CRC earned a bachelor's degree in psychology and a master's degree in rehabilitation counseling from the University of Kentucky. He is a certified rehabilitation counselor employed in a private forensic practice where he performs vocational evaluations as well as provides vocational expert testimony for the Social Security Administration. Mr. Rymond's professional interests include earnings capacity and work life estimates of individuals with disabilities.

Kathy Sheppard-Jones, PhD, CRC is the executive director of the Human Development Institute at the University of Kentucky, Kentucky's University Center for Excellence in Developmental Disabilities Education, Research and Service. She is an adjunct assistant professor in the Clinical Rehabilitation Counseling Program at the University of Kentucky. She received her doctoral degree in educational psychology from the UK. She works across projects around employment systems change, health education, home modifications, quality assurance, community inclusion, and driver rehabilitation.

Elizabeth Siereveld has been a staff physical therapist at the University of Kentucky Chandler Medical Center in Lexington, Kentucky, since 2005. She received her undergraduate degree from Transylvania University in Lexington, Kentucky, with a focus on exercise science. She then received her master's and doctorate degrees in physical therapy from the University of Kentucky with a focus on acute care in a level 1 trauma center. Elizabeth has been involved in several different service learning opportunities in Ecuador and India while being affiliated with the University of Kentucky. While in India and Ecuador, Elizabeth has provided direct client care to underserved populations of all ages while participating in an interdisciplinary focused team approach. That allows collaborations with healthcare providers as well as special education providers.

Amy D. Spriggs, PhD is an associate professor of special education at the University of Kentucky. She received her bachelor's, master's, and doctorate degrees in special education from the University of Georgia. She teaches classes in methods, assessment, and research for individuals with moderate to severe disabilities at the undergraduate and graduate level. Each spring, Amy leads a service learning trip to a small rural village in Southern India. There, she partners with interdisciplinary teams of parents, teachers, therapists, doctors, and students to assess children and adolescents with various disabilities. The team works together to create intervention plans for the special education school, home, community, specialized programs, and the general education school, as appropriate. Amy spends time each year training the staff for sustainable implementation of interventions.

Matthew E. Sprong, PhD is an assistant professor in the Rehabilitation Counseling and Rehabilitation Services program at Northern Illinois University. His primary areas of research include public and private sector rehabilitation counseling service delivery, substance abuse and addictive behaviors, and disability equity and post-secondary education.

David Staten, PhD, CRC is a professor in the Rehabilitation Counseling Program at South Carolina State University. He is a licensed professional counselor. His primary area of research focuses on racial identity development of minorities with disabilities, health orientations of African-American college students, and health disparities of minorities with disabilities. Additionally, he has over 10 years of administrative experience as the program director of the rehabilitation counseling program and several years of experience serving as department chair.

Pamela B. Teaster, PhD is a professor and associate director of the Center for Gerontology at Virginia Tech. She established the Kentucky Justice Center for Elders and Vulnerable Adults and the Kentucky Guardianship Association and was its first president. Her scholarship areas include the mistreatment of elders and vulnerable adults, public and private guardianship, end-of-life issues and decision-making, public policy and public affairs, public health ethics, and quality of life. She is the coauthor of two books and of over 100 peer-reviewed articles, reports, and book chapters.

Lebogang Tiro, ME, MRC, CRC is a student in Rehabilitation Counseling Education, Research, and Policy Doctoral Program at the University of Kentucky. She received her master of education in counseling from Botswana and her master of science in rehabilitation counseling from the University of Kentucky. Ms. Tiro has been an educator for 13 years in a primary school in which she was head of the Department for Learning Disabilities. Her research interest is in the area of neurological disorders including brain injuries, multiple sclerosis, spinal card injury, and narcolepsy.

Sara VanLooy, BA has worked at YTI since 1999 as an administrative assistant and publications assistant, providing research, editing, administrative, and writing support on numerous projects. She currently provides research and editorial support to the YTI research team and to the Employer Practices Rehabilitation Research and Training Center Grant.

Sarah von Schrader, PhD received a PhD in educational measurement and statistics from the University of Iowa. She now serves as the assistant director of research at the Yang Tan Institute in Cornell University's ILR School. Sarah's research focuses on employer practices related to employer success in recruiting, hiring, and advancing individuals with disabilities. She also evaluates the process and impact of several of the programs offered by the Yang Tan Institute.

Veronica I. Umeasiegbu, PhD, CRC is an assistant professor with the School of Rehabilitation Services and Counseling, at the University of Texas Rio Grande Valley. She obtained her master's degree in rehabilitation counseling from the University of Pittsburgh and her PhD in rehabilitation counseling education, research, and policy from the University of Kentucky. She served as an intern with the Disability and Rehabilitation Unit of the World Health Organization (WHO) in Geneva, Switzerland, in 2008. She has authored several book chapters and peer-reviewed journal articles. Her research interests include psychosocial and adaptation issues in disability and chronic illness, health disparities, resilience and self-advocacy, sexuality in disability, and international disability issues.

Daniel W. Wong, PhD, CRC is a professor in the Department of Counseling, Educational Psychology and Foundations, College of Education, at Mississippi State University (MSU). Prior to his tenure at MSU, Dr. Wong served as professor and director of the doctoral program in the Department of Rehabilitation Studies, College of Allied Health Sciences, and adjunct professor in the Department of Physical Medicine and Rehabilitation at Brody School of Medicine at East Carolina University. He has taught at the University of North Texas, San Jose State University, Hofstra University, and the University of Hawaii at Manoa.

Thomas Young is the Jim and Suzanne Elliott & Family professor of pediatrics at the University of Kentucky. He is the founder and serves as chair of Shoulder to Shoulder Global (STSG) at the UK. STSG operates a health center in Ecuador; partners in the children with special needs center in Mayasandra, India; and leads service learning trips to both countries. He has been participating in the Mayasandra, India, project for 6 years and participated in the planning and implementation of this project. In pediatrics, his work is in general pediatrics, developmental and behavioral pediatrics, global health, and school health.

Part I

Community Characteristics and Issues in Rural, Frontier, and Territory Communities

1

Entrepreneurship and Economic Development in Rural America

Ronald J. Hustedde

Overview

Americans with disabilities and rural communities have something in common: both struggle to build assets and to create wealth. Yet, both have opportunities for building a quality of life that is rooted in equity and prosperity. Rural people and those with disabilities start their own ventures due to decreased employment opportunities. The World Bank (2016) reports small and medium enterprises account for more than half of all formal jobs across the globe. These firms create effective solutions for clean water, alternative energy, health services, and education. During 1992–2005 smaller companies created more jobs than larger companies. However, recent research indicates start-up firms, regardless of size, and generates the greatest surge of jobs in the USA (Haltiwanger et al., 2012). Small firms account for almost two-thirds of employment in rural America (U.S. House of Representatives Small Business Committee, 2016).

Entrepreneurship is seen as a route to economic independence for people with disabilities. According to Kitching (2014), one possible solution to problems of low labor market participation rates lies in the potential for people with disabilities to become self-employed or to start and run their own businesses. The risks of poverty and barriers to employment are significantly higher for people with disabilities in rural areas than for people without disabilities and for people residing in urban areas. The reasons for both risks and low employment rates are attributed to a wide range including level of education, local job market, social exclusion, and geographical boundaries in rural areas.

Learning Objectives

By the end of the chapter, the reader should be able to:

1. Describe disabilities and entrepreneurship in rural areas.
2. Explore the economic and community obstacles and opportunities that people with disabilities in rural areas face.
3. Build a case for entrepreneurship as a venue for creating wealth and prosperity among those with disabilities in rural areas.
4. Provide insights on how rural communities and advocates for people with disabilities can build an entrepreneurial culture and ecosystem.

Introduction

People can consider entrepreneurship and/or self-employment for various reasons: (a) out of necessity, (b) attempt to increase their income, (c) gain independence and autonomy, (d) take advantage of an opportunity, and (e) improve work-life balance (Potter & Halabisky, 2014). These reasons may also influence people with disabilities; however, they are also likely motivated by different

R.J. Hustedde (✉)
Department of Community and Leadership Development, University of Kentucky,
Lexington, KY, USA
e-mail: Ronald.hustedde@uky.edu

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factors such as the benefit that entrepreneurship provides as entry into the labor market, a buffer against employer discrimination, and flexibility in work hours and accommodations (Jones & Latreille, 2011). "In addition to facing the general challenges to business start-ups that all entrepreneurs face, entrepreneurs with disabilities are likely to face specific barriers to entering and sustaining entrepreneurship activities" (Potter & Halabisky, 2014, p. 8; see Table 1.1).

People with disabilities in rural communities present unique challenges with regard to the desirability and feasibility of entrepreneurship. Moreover, barriers exist to the availability of entrepreneurship training, technology, mentors and advisors, and local incentives and tax credits. Although entrepreneurship offers expanded opportunities for people with disabilities in rural areas, it is important to understand the contextualized social-structural and geographical constraints that rurality imposes on economic development and inclusion of people with disabilities.

Table 1.1 Barriers to entrepreneurs with disabilities

Lack of confidence and limited aspirations – difficulty identifying a business opportunity, developing this business idea, and engaging with the available support infrastructure in a meaningful way; unsupportive family and friends
The benefits trap – fear of losing the security of regular benefit income (supplemental security income or social security disability income)
Lack of relevant business knowledge and skills – lack of specialist business management, legal, and financial skills and knowledge due to limited relevant education and employment experience
Access to start-up capital – limited personal financial resources; poor credit rating; disinterest/discrimination part of the banks; lack of accessible information on sources of grants and loans
Consumer discrimination – result in reducing the demand for goods and services produced
Increased labor costs – some entrepreneurs with disabilities need to hire assistants to help them undertake tasks that many non-disabled people can do on their own
Lack of appropriate business support services – business advisers are often reluctant to recommend self-employment as a career option for people with disabilities and sometime actively dissuade them; inadequate or stereotypical understanding of the activity restrictions related to the disability

Adapted from Potter and Halabisky (2014)

Link Between Rural America and Disabilities

Over the past decade, researchers have asked whether there is a relationship between geography and disability. Information about that question was released in 2013 by the US Census Bureau from the 2008 to 2012 American Community Survey. Self-reported disabilities from the survey are defined as functional impairments in at least one of the six areas: hearing difficulty, vision difficulty, cognitive difficulty, ambulatory difficulty, self-care difficulty, and the inability to live independently. There are also distinctions between severe and non-severe disabilities.

While metropolitan counties have a disability rate of 11.2%, the rate is more pronounced in nonmetropolitan counties. Counties with populations between 50,000 and 10,000 people have a disability rate of 15.2%, while noncore counties with populations of less than 10,000 have a rate of 17.4%. Although nonmetropolitan counties have higher population rates of those who are 65 and older, there are consistently higher rates of disabilities in nonmetropolitan counties across all age ranges. These nonmetropolitan counties represent about 72% of the US land mass (von Reichert, Greiman & Myers, 2014).

Differences of Living in Urban and Rural America

Rural Americans tend to be less influential in affecting US federal policy because they only represent about 14% of the US population (USDA Economic Research Service, 2017). Partisan differences about the environment, worker and food safety, and agricultural issues make it difficult to build coalitions between rural and non-rural legislators. As a consequence, rural America lacks a comprehensive federal rural development policy (Hustedde, 2008). Rural residents may be more effective in stimulating needed changes at the regional and local levels to reflect the uniqueness and diversities of their communities (Fortunato, 2014).

The rural landscape is distinguished from urban areas by income, education, employment levels, and the role of gender in small business development.

Income Disparities Rural residents tend to have a lower income levels than their urban peers. These differences can limit access to good and services that can fuel economic development. It also means that rural residents may not be able to leverage as much capital for entrepreneurial opportunities. Rural median household income was $41,198 in 2012, while the urban median household income was $52,988 in the same year (Kusmin, 2015). Typically, income level is directly proportional to education attainment.

Educational Levels Land, labor, and capital were once viewed as the essential ingredients for economic development. However, education is now viewed as a critical fourth ingredient for the knowledge economy, particularly for innovative approaches to address pressing issues associated with health, environment, and other needs (Shaffer, Deller, & Marcouiller, 2004). Knowledge and skills cannot always be measured by formal educational attainments, but that is the measure that is available. Rural areas have made educational gains, but they still lag behind urban areas. Approximately 35% of urban areas have working-age adults with 4-year college degrees versus 19% in rural areas (Kusmin, 2015). The higher concentration of employment opportunities for college-educated adults in urban areas continues to draw people away from rural areas.

Employment Employment can be part of a downward or upward spiral for economic development. An area with high employment can lead to higher wages because of the competition to secure workers. The obvious consequences can be a more potent economy and higher quality of life. On the other hand, higher levels of unemployment can set the stage for a downward spiral regarding the quality of life and prosperity. Some unemployed and underemployed people will turn to entrepreneurship as a venue for sustainable income. Unemployment is higher in rural counties with less formal education. Educational rates are lower for racial and ethnic minorities in rural counties.

Rural businesses and consumers are as likely to use the Internet as their urban counterparts. However, broadband access is not as readily available in rural areas, and the lack of population densities leads to higher costs and a less pronounced return on investments (see Chap. 4 for additional information on technology).

Gender Women from rural areas tend to have less access to employment opportunities than urban women. Hence, a higher proportion of women from rural states are small business owners. A South Dakota study of rural women business owners indicates that the majority had gross sales of less than $100,000. These women defined success in four major categories: (a) helping others, (b) contributing to family income, (c) making a profit, and (d) feeling a sense of accomplishment. Most of the respondents indicated that being a woman was a positive or neutral factor toward their business success (Meeder & Cumber, 2007). See Chap. 11 for additional information on women in rural communities.

Summary The differences in urban and rural areas are pronounced. Only 14% of Americans live in rural areas. There isn't a comprehensive federal policy for rural development because of partisan differences and unidirectional metropolitan communication linkages. Urban residents have higher rates of formal education and income than rural residents. Educational levels may impede involvement in the knowledge economy, and lower income could mean that rural people will be able to leverage fewer resources for economic development than their non-rural counterparts. Unemployment in rural areas tends to be higher, especially for women and minorities. However, women in rural areas are more likely to start businesses because of limited economic opportunities. In recent years, there have been intellectual shifts in community development practices. The focus is no longer on deficits or problems but on assets or strengths. Rural regions can discover their unique cultural, financial, environmental, and infrastructure assets and build on those strengths.

Defining Entrepreneurship

An entrepreneur can be defined as an individual (or team) who creates a new business venture within a place that offers a new product(s) or service(s) and adds value to markets within the community. It can include innovative replication or introduction of a prior innovation to a new market or to an old market in a novel way (Fortunato, 2014). Contrary to popular opinion, entrepreneurs are not huge risk takers. They tend to take calculated risks and share those risks with investors, partners, community, and others.

While business owners have entrepreneurial traits to stay in business, all of them are not entrepreneurs. Some business owners are managers who routinely open and close their businesses each day. The Ewing Marion Kauffman Foundation claims that business owners who revitalize, grow, and reinvent their business are inherently entrepreneurs, while other business owners who are merely maintaining their operations are behaving more as managers (Markley, Mackey & Luther, 2005).

Sirolli (2012) argues against the myth of the entrepreneur as a single individual. He contends that the most successful entrepreneurs consist of teams who are skilled in three areas: (a) the development of a product or service, (b) marketing or sales, and (c) finance, including anticipated sales, overhead, and potential profits. While some individuals may be talented or drawn to two of these areas, they are seldom accomplished in all three. The team concept makes it easier for individuals who may have disabilities to focus on their strengths rather than perceived limitations.

Entrepreneurs seize opportunities. They may not invent the idea, product, service, or approach, but they see value in something and carry it toward action. Contrary to popular opinion, their primary motivation is not exclusively about financial gain. They are driven by passions – the ability to make a difference in people's lives, to provide employment to others, to create a lifestyle, or to prove their creative spirit (Gruidl & Markley, 2015).

Entrepreneurial Types

Entrepreneurs are not the same. It can be argued there are at least six kinds of entrepreneurs. These are discussed below.

Aspiring entrepreneurs include those people who have not started a business or venture yet because their timing isn't right. They may be researching their idea, or they may lack encouragement, partners, and finances or face other difficulties or limitations. Start-ups have taken the plunge and actually launched their enterprise, but they may not have a solid business plan or have not fully developed their team. The needs of aspiring and start-up entrepreneurs are similar. They often need community support, mentoring, training, or business counseling.

Survival entrepreneurs include those who start a venture because of unemployment or the need for supplemental income. They are not necessarily growth oriented because what they really want is a job with fixed wages and benefits. Typically, they are not considered part of conventional community economic development strategies because they are part of the informal economy and often act on a cash basis. Nevertheless, there is a growing awareness that these kinds of businesses are important. Nonprofit microcredit services, modeled after the Grameen Bank in Bangladesh, have emerged in the USA to provide loans and other financial services to people who cannot access conventional loans or credit. In order to access microcredit, these entrepreneurs are usually required to receive financial literacy and business planning, training, and counseling to insure their success (Dewan, 2013). Survival entrepreneurs can move toward growth with community encouragement and visioning.

Lifestyle entrepreneurs are attracted to a place or business that suits their idea of a good life. They may run a bed and breakfast establishment, a hardware store, and a fly-fishing business or serve as a family physician. While there are numerous and successful lifestyle entrepreneurs, they typically don't have aspirations to grow.

Growth-oriented entrepreneurs are driven to grow their sales and profits and to build their new products or services. The entrepreneurship literature refers to them as "gazelles." Many regional and state entrepreneurship policies attempt to identify the potential high-growth businesses and provide assistance to help them expand. They are seen as major job and wealth creators because they have compounded growth rates of 15% per annum. These firms represent about 4–5% of American businesses.

Civic or social entrepreneurs have the same motivations as other entrepreneurs. However, they tend to work in teams with an emphasis on interdependence and inclusivity. They start with an optimistic view of the local or regional economy and bring their entrepreneurial mind-set to the civic arena. Their long-term interests and the community's interests complement each other. These civic entrepreneurs fall along the continuum from for-profit businesses to nonprofits. While they generate sufficient revenue to be sustainable, they address issues related to the environment, social justice, or sustainable economic development (Kerlin, 2006; Murray, 2012). These ventures may also take on the form of a cooperative or an employee-owned business. In recent years, "B" corporations have emerged and are certified by the B Lab, a nonprofit organization that focuses on a shared and durable prosperity, transparency, and a positive impact on the community (B Lab, 2016).

Youth entrepreneurship is another important component to consider. National surveys indicate that most high school youth are interested in starting their own businesses (Markley et al., 2005). Their involvement in entrepreneurship is of vital concern to rural communities for retaining their youth and encouraging them to innovate and use their talents to create wealth and jobs. The key is to provide opportunities for them to learn about the business world and to learn entrepreneurial skills. The impact from entrepreneurial programs in schools and other organizations such as 4-H or Junior Achievement is significant: an increased interest in education, problem-solving, practical skills in teamwork and financial management, and leadership skills and interpersonal skills (Kaufmann & Stuart, 2007). The challenge for communities is to develop high-quality entrepreneurship programs. Youth entrepreneurship initiatives have emerged in rural America to provide economic alternatives based on rural assets and to avoid the "brain drain" to urban areas. Organization such as the Future Farmers of America and programs in the Cooperative Extension System are focusing more resources on youth entrepreneurship (Schroeder, Heinert, Bauer, Markley & Dabson, 2010).

Challenges for Rural Entrepreneurship

Rural America has a rich entrepreneurial tradition that is part of the American identity: it has attracted immigrants and people with imagination. During the industrial age, improvements in agricultural, mining, and extractive technologies created new opportunities for entrepreneurs that strengthened rural economies and quality of life. While urban areas have outpaced the growth of rural areas during the past 50 years, rural areas are no longer dependent on farming, forestry, and mining. Rural economies have shifted into manufacturing, tourism and recreation, and a variety of service-based industries. These shifts require funding and other resources for start-ups and expansion including product and market research, operations, and sales. The funding issue is more pronounced for entrepreneurs who are seeking exponential growth.

Finances for Rural Entrepreneurs

The ecosystem for rural entrepreneurship has shifted during the past 20 years. It used to be about finding capital from commercial banks or relying on personal resources including those from friends and family. However, the range of players has broadened to include public financing programs, microlending for small businesses, community development financial institutions, formal and informal investment groups, US Department of Agriculture and Small Business Administration programs, and crowd financing. Rural businesses are more likely to use traditional tools such as bank and debt capital and are less likely to use equity capital such as crowd funding or angel investment groups. Rural entrepreneurs may be less likely to take on more debt than urban peers. There are also geographic disparities in the distribution of bank and public sector financing in some rural counties. Some rural areas have more robust demand for alternative financing than others because of a less sophisticated ecosystem or local public policies that are less favorable for entrepreneurs (Markley, Pages, Scruggs, & Miller, 2012).

Limitations for Rural Entrepreneurs

The higher population densities of urban American with concentrated services make it easier for urban entrepreneurs to access equity finances, technical assistance, institutional support for small businesses, and proximity to markets. The remoteness of rural areas and strong ties with kin and close friends can restrict information flows and can isolate rural entrepreneurs. Lop-sided power relationships of dominant employers and elites in rural areas can also disempower citizens. In addition, many rural counties have experienced "brain drain" – population shifts of college-educated adults to urban areas where there are more economic opportunities. While those lacking a college education in rural areas are more likely to be self-employed, they don't generate as much income as college-educated entrepreneurs (Fortunato, 2014). While rural firms are more persistent and have better survival rates than urban firms, they tend to have slower growth rates and generate fewer jobs than their urban counterparts. The slower job growth rates can be attributed to smaller home markets and limited access to business services including coaching and mentoring (Markley et al., 2012).

Opportunities for Rural Entrepreneurship

In spite of these limitations, rural locations have advantages for entrepreneurs of all types. Rural self-employment has outpaced urban self-employment by taking advantage of access to natural resources and lower costs of land and labor. Family farms are turning to agritourism such as farm stays, agricultural festivals, and pick-your-own produce (Gartner, 2004). In addition, value can be added through direct sales to consumers or moving from nonorganic to organic, planting different crops, raising different animals, or adding something to a raw commodity such as the production of jam or sausage. They can also find ways to save energy or make their products viewed as superior to other competitors (Lu & Dudensing, 2015).

Lifestyle entrepreneurs are often attracted to rural areas because of the scenery and outdoor recreation or to escape the pressures of urban life. These exurbanites can draw upon the Internet to launch information-based businesses with export-oriented links to outsiders. Other lifestyle entrepreneurs are drawn to tourism-related entrepreneurship, apparel, retail, interior design, and hospitality firms because they want to live in a certain place or maintain a lifestyle without the confines of traditional employment (Fortunato, 2014).

Civic or social entrepreneurs are driven by the need to bring about some form of social change. The rural landscape is dotted with civic ventures that focus on issues such as affordable and safe housing, alternative health care, asset-based economic development, arts and artisans, environmental conservation, disability rights, youth development, and community-based philanthropic organizations. Capital access has been a problem for these entrepreneurs, but web-based intermediaries, socially conscious investors, and the growth of local philanthropies are minimizing some of these obstacles (Bornstein, 2007; Bornstein & Davis, 2010; Harris et al., 2013; Shapiro, 2012). Social entrepreneurs are also being nurtured through business schools and other institutions that integrate social issues with business concepts. For example, Berea College in Kentucky has a multiyear undergraduate program, *Entrepreneurship for the Public Good*; its intent is to help rural communities in Central Appalachia. According to the organization's website, the primary focus is on "a process when one person or a group of people in a community originate an idea or innovation for a needed change and influence others in that community to commit to realizing that change, despite the presence of risk, ambiguity, or uncertainty" (*Entrepreneurship for the Public Good*, 2016).

Rural youth entrepreneurship is becoming more visible as community development strategy because it engages youth in creative learning and problem-solving business acumen and provides alternative economic choices. Rural-dominated organizations such as the Future Farmers of America and the Cooperative Extension System are creating more venues for youth to be innovators (Guthrie, 2013). The Center for Rural Development learned that the key to rural entrepreneurial communities is to attract youth and keep them there. There are strong emotional ties to families, friends, and groups that can keep youth involved if they believe that educational and economic opportunities are available to them. Communities have often, unintentionally, not involved youth in shaping their own futures and local development efforts. Based on their study of over 6000 youth in the Midwest, the Center recommends these action steps:

1. Create a community action plan for improvement that actively engages youth.
2. Encourage the growth of medium- and small-sized businesses through coaching and technical assistance that offer employment and ownership opportunities for youth.
3. Introduce entrepreneurship into the school curriculum or as an extracurricular activity with links to entrepreneurs who can serve as mentors or provide hands-on activities for aspiring entrepreneurs.
4. Consult and involve local youth in every aspect of community development efforts as a way to build new leaders (Dabson, Schroeder & Markley, 2010).

Opportunities for Rural Entrepreneurs and People with Disabilities

More than 8.8 million noninstitutionalized civilians with disabilities live in rural America (U.S. Census Bureau, 2015). Historically, Western societies have institutionalized or marginalized those with disabilities. However, the past 30 years have witnessed marked changes because of social movements that focused on inclusion. The Americans with Disabilities Act (ADA) of 1990 is modeled after laws that prohibit discrimination based on race and gender. The ADA covers disabilities related to mobility, stamina, vision, hearing and speech, learning disorders, and emotional illnesses. It addresses access to the workplace, state and local government, places of accommodation, and commercial facilities and telecommunications for people who have hearing or speech impairments through telecommunications relay services.

In spite of these gains, the 2015 unemployment rates for those with disabilities were 10.7%, while those with no disabilities was 5.1%. About 32% of workers with a disability were employed part time, while 18% of those with no disability have part-time jobs. Working-age people with a disability were more likely to be self-employed than those without a disability (U.S. Dept. of Labor, 2016).

There are risks for entrepreneurs who carry the weight of their operations on their own shoulders and spread themselves too thin. Hence, policy makers have created programs to share risks for entrepreneurs with disabilities. These efforts are also part of a pattern of inclusivity by federal and local governments and nonprofit groups. At the federal level, there are a variety of initiatives to create self-employment for those who are disabled. Table 1.2 lists entrepreneurial resources for people with disabilities.

While the initiatives listed in Table 1.2 are noteworthy, it is only in recent years that scholars have attempted to bridge the gaps among entrepreneurship studies, rural studies, and disabilities studies.

Arnold (2011) conducted the first national study of those who are disabled and self-employed. She found that over half of entrepreneurs with disabilities had initial investments of less than $10,000 to start their businesses. They reported that their investments came from one of more sources: personal savings (59%), credit card/cash advance (30%), loans from family members (25%), institutional loans (18%), and state vocational rehabilitation funding (16%). There were a variety of reasons why they started business including wanting to be their own boss and seeing a need for a product or service. Forty-three percent cited the need to accommodate their disability through flexible work hours or working conditions. The typical entrepreneur with disabilities in this study of 330 respondents was a white male with some college education. Their businesses were diverse: construction contractors, manufacturers, artisans, farming/ranching, retail, and providers of various services. Fifty-two percent reported their disability affected how they ran their business. Nine-one percent enjoyed their business, and 56% reported their business as "successful."

There are several studies that have attempted to identify the key variables that influence how entrepreneurs with disabilities can be nurtured. Heath and Reed (2013) identified 38 low-income entrepreneurs with disabilities in Alaska, including those from rural areas. Their program offered training sessions on topics such as marketing and financial management that was followed up with networking sessions on building social capital and one-to-one support from other entrepreneurs. A web-based conferencing system was used because some of the participants lived as far as 1000 air miles from each other. While many entrepreneurship initiatives focus on technical aspects of developing a business, this industry-driven support model promised a low-cost effective method for entrepreneurship because they concluded that the focus on social capital addressed the geographic isolation and connected them to other low-income entrepreneurs and to others in the field. The one-to-one mentoring was also effective:

- The Chicago Add Us In (AUI) program was funded through the US Department of Labor to remove environmental barriers that inhibit entrepreneurship among the disabled. It built a consortium among key institutions including hospitals and rehabilitation centers to view entrepreneurship as an alternative to wage employment. The consortium offered courses to develop business plans and provided mentoring and a business incubator for start-ups. They also explored the creation of small cooperatives as venues for people with disabilities to become co-owners rather than sole propri-

Table 1.2 Entrepreneurial resources for people with disabilities

Federal resources
Small business administration: https://www.disability.gov/
Office of Disability Employment Policy (ODEP), US Department of Labor: https://www.dol.gov/odep/resources/
Other resources that provide training, encouragement, and networking assistance
Disabled Businesspersons Association offers entrepreneurship education courses for those with disabilities: http://disabledbusiness.org
DisabilityBiz.org offers business plan training and consulting for disabled entrepreneurs: http://www.disabilitybiz.org
Entrepreneurship Bootcamp for Veterans with Disabilities offers experiential training in entrepreneurship and small business management to post 9/11 veterans: http://ebv.vets.syr.edu/
The Global Network for Entrepreneurs with Disabilities provides information for entrepreneurs at various stages of their journey: http://entrepreneurswithdisabilities.org/
The Hadley Institute for the Blind and Visually Impaired offers entrepreneurial online courses for those with vision impairments: http://www.hadley.edu/
Job Accommodation Network contacts entrepreneurs with disabilities to others in their field: http://www.careersbeyonddisability.com
University of Montana Research and Training Center on Disability in Rural Communities investigates approaches to help rural rehabilitation service providers to help those with disabilities to achieve and maintain employment: http://rtc.ruralinstitute.umt.edu/employment-vocational-rehabilitation/

etors of businesses. The consortium of various agencies generated systems changes that improved the opportunities for people with disabilities to become self-employed. The "lessons learned" from this initiative are:

- Relationship building among agencies is key to success.
- Troubleshooting and assessing progress is part of facilitative leadership.
- Through cooperative efforts among agencies, entrepreneurship can empower people with disabilities.
- Trusting relationships and collaboration among agency leaders create the ingredients for systems changes.

The consortium requires more work because agencies have to gradually change their culture and openness to entrepreneurship (Balcazar, Kuchak, Dimpfl, Sariepella & Alvarado, 2014).

Veterans and Entrepreneurship

Among the 2.3 million individuals who have served in the US military forces since 9/11, one in every four has a service-related disability (see Chap. 8 for discussion on veterans). Veterans are likely to have a variety of military skills and knowledge that can be transferred to civilian life. Evaluations of the Entrepreneurship Bootcamp for Veterans with Disabilities indicate that hobbies and self-employment should not be confused with creating a business. Blass and Ketchen (2014) learned that veterans who started businesses are most likely to succeed if the firms are based on three factors. First, they have a value proposition – why a customer would spend money with that business rather than another organization. Second, successful businesses leverage the unique experiences and attributes of the entrepreneurial team including military experiences. Third, the business is built around a process or system that prospers even if the entrepreneur leaves. These three factors are also applicable to nonveterans.

The Viability of Entrepreneurship for Those Who Have Disabilities

In a review of key literature about entrepreneurs and disabilities, Arnold and Ipsen (2014) concluded that entrepreneurship is an important economic development strategy for those involved in vocational rehabilitation. It provides a viable option for those with disabilities because it offers flexible scheduling to address health issues, increases economic independence, and allows people to stay closed to supportive networks. Government policies can help entrepreneurs with disabilities to succeed.

However, there is a trade-off when government organizations invest in generic programs but do not have resources to adapt those programs to meet the broad spectrum of those with disabilities (Kitching, 2014).

People with disabilities have seldom been involved in community economic development initiatives, nor have rural community development strategies generally reflected the well-being of those with disabilities. Admittedly, it can be cumbersome to generate inclusive representation of the disabled, women, immigrants, and youth. However, research indicates those rural communities that have multiple stakeholder representation and leadership tend to have greater economic impacts (Ipsen et al., 2006). Vocational rehabilitation programs and rural Centers for Independent Living (CILs) are untapped resources for integrating those with disabilities into leadership positions, employment, and small business development. A study of citizen-led rural community development efforts in two states indicates that there were multiple outcomes:

- It changed the views of locals who viewed those with disabilities as assets because they took on leadership roles where others did not.
- Alternative economic development strategies were pursued rather than merely competing for large-scale industrial plants.
- Community people came to see the role of vocational rehabilitation in overall economic development.
- A greater sense of solidarity emerged among community people.
- The capacity of citizens to promote community development was enhanced through engagement (Ipsen et al., 2006).

Enhancing Rural Entrepreneurship Among People with Disabilities at the Local Level

Entrepreneurship is more than government or private agency support programs or individuals who have a hunger to follow their passions and create innovative enterprises. It involves a culture or mind-set (Hustedde, 2007) that stimulates shared learning and a systems approach. A learning community questions the *status quo*, discovers and shares new knowledge, and changes behavior to reflect its learning (Gruidl & Hustedde, 2003). The second premise involves strengthening the entrepreneurial ecosystem. Typically, rural communities neglect to question the gaps or missing parts in an entrepreneurial system or how the parts are interconnected. New frameworks are needed to animate people for fostering entrepreneurship. Systems thinking aligns technical assistance and financing programs and involves institutions at all levels (Dabson, Malkin, Matthews, Pate & Stickle, 2003; Macke and Markley, 2006). Advocacy groups need to move away from an exclusive focus on finding employment for those who are disabled. If they want to nurture independence and economic security, they also need to see themselves as economic partners in strengthening the local and regional systems for entrepreneurship. Abstract discussions about a learning community and a systems approach are likely to be frustrating for readers who want practical applications of these principles. Hence, seven approaches for fostering an entrepreneurial ecosystem and culture are suggested.

First, it is important *to make a case for entrepreneurship*. It is in the self-interest of rural communities, vocational rehabilitation organizations, Centers for Independent Living, and those with disabilities to explore the promise of rural entrepreneurship. It is more than just small business. It is about innovation to meet needs and wants: mobilizing resources, sharing risks, building teams, and carrying that into for-profit or nonprofit ventures including cooperatives and B corporations. Entrepreneurship is linked to rural vitality. A systems approach focuses on entrepreneurs and their range of personal and business needs and building supportive entrepreneurial communities. The case can be made for the spectrum of entrepreneurs that add to a community's quality of life and economic prosperity: survival entrepreneurs, lifestyle entrepreneurs, medium-sized businesses, growth-oriented entrepreneurs, civic and social entrepreneurs, and youth entrepreneurs. Unless a community can articulate the promise of entrepreneurship, local policy makers are likely to fall back on investing meager resources in industrial recruitment and attraction and ignoring the promise of entrepreneurship (Macke & Markley, 2006).

Second, rural communities need to *welcome fresh voices and to embrace inclusivity*. Those communities that welcome youth, immigrants, women, and the disabled to the table will achieve a great sense of belonging and a willingness to set goals and to bring about change. Those who are disabled may be reluctant to be involved in local organizations unless they are invited (Ipsen et al., 2006, p. 65), but they make up a significant part of rural America.

Third, communities and service groups for those who are disabled need to *mobilize resources for entrepreneurs* to thrive. A systems approach is needed. Consortiums need to be created among agencies, government institutions, and other organizations to lessen barriers for self-employment among those who are disabled (Balcazar et al., 2014). Some communities have turned unused space or empty downtown stores into incubators with low rents and technical assistance for entrepreneurs to thrive in the areas of arts, agriculture, manufacturing, technology, and youth entrepreneurship. Several Iowa communities offer monthly technical assistance workshops for entrepreneurs to start or expand. Other communities have programs that link entrepreneurs and their ideas for expansion with informal investors on a regular basis.

Fourth, communities and those who served those who are disabled need to *focus on assets rather than deficits*. Kretzmann and McKnight (1993) revolutionized the field of community development when they questioned those in the most economically distressed communities in America about their strengths and assets including their skills, talents, and hidden resources. Asset mapping continues to inspire communities to focus on the positive and to build new opportunities. Those who are disabled as well as women, immigrants, youth, and others can become more involved when they see assets in themselves and others including cultural assets, natural assets, built assets, financial assets, political assets, social capital, and human capital (Emery & Flora, 2006). Entrepreneurship can be part of a community's wealth creation strategy. It can also enhance the environment and add to a community's quality of life (Markley & Stark, 2013).

Fifth, it is important to *cultivate networks for entrepreneurs to thrive*. As discussed earlier, entrepreneurial teams are more successful than loners. Individuals in a team can complement each other's strengths and weaknesses. Entrepreneurs with disabilities need full-time or part-time partners like any other business. In addition, entrepreneurs need to be exposed to a variety of models including small cooperatives. It is also important for those with disabilities or other perceived limitations to hear stories from entrepreneurs who have faced and overcome difficulties. Entrepreneurial recognition programs and other events can encourage entrepreneurial networking among different age groups, ethnic backgrounds, income levels, and other interests. Peer learning is one of the most effective tools for people to learn more effectively.

Sixth, communities, regions, and states need to develop a *shared vision about entrepreneurship*. If a community or region knows its assets and understands market potentials, it can develop a big picture of its future including an entrepreneurial focus in areas such as the arts, alternative energy, agriculture, recreation, and other venues. To be effective and compelling, these visioning initiatives must include those who are disabled, youth, women, and people from various ethnic and income backgrounds. An entrepreneurial ecosystem integrates entrepreneurship into school curriculums as part of a continuous learning and explores issues such as the demand and supply of debt and equity capital and technical services for business and civic innovators.

Seventh, *communities need to foster entrepreneurial leaders and advocates* to help the community and region to prosper. In helping entrepreneurs to recognize opportunities and build new ventures, communities can enhance their economy, improve their environment, and expand the diversity of people involved in public life (Markley & Stark, 2013). Vocational rehabilitation organizations and Centers for Independent Living must find ways to nurture leaders to advocate for entrepreneurs and strengthen the ecosystem for entrepreneurship to grow and mature. Questions must be explored about who is missing in alternative economic development strategies including youth, those from different ethnic backgrounds, income levels, or disabilities. Entrepreneurial civic leaders can also help small-scale entrepreneurs to move toward growth stages to serve new markets or provide new services or products by linking them with resources and networks or helping to craft local policies to foster expansions.

Summary

This chapter blends rural studies with scholarship about entrepreneurship and disabilities. It describes the level of disabilities in rural areas and explores the definitions and spectrums of entrepreneurship. There are similarities between urban and rural entrepreneurs with disabilities, but rural areas have limited supportive services for entrepreneurs. However, there are unique opportunities for rural entrepreneurs that include natural resources, alternative energy, recreation, and other possibilities.

While federal policies and private initiatives can be helpful for rural entrepreneurs who are disabled, local communities must build an inclusive entrepreneurial culture that builds a learning community and involves a systems approach in which parts are interlinked. Seven practical strategies are offered for rural communities to build an inclusive entrepreneurial culture and an entrepreneurial ecosystem.

Learning Exercises
Self-Check Questions

1. What are some of the reasons that people with disabilities consider entrepreneurial activity?
2. What are the different entrepreneurial types?
3. What is the argument in favor of entrepreneurs consisting of teams rather than individuals?
4. What are the differences between urban and rural entrepreneurship?
5. How can entrepreneurship be enhanced for people with disabilities at the local level?

Experiential Activities

1. Interview an individual with a disability in a rural area that is engaged in entrepreneur activity or is self-employed, and report on how he or she got started and how he or she is maintaining the enterprise.
2. Meet with a local business owner, and discuss what is necessary to develop a business plan for a self-start business.
3. Identify an incubator for small business development in your local community, and determine available resources to assist in the development of entrepreneurial activities.
4. Interview a rehabilitation counselor that has a rural caseload, and discuss if he or she has assisted clients to become self-employed and what supports and strategies were used.

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Disability, Income, and Rural Poverty

2

William A. Erickson, Sara VanLooy, Sarah von Schrader, and Susanne M. Bruyère

> *Poverty anywhere is a threat to prosperity everywhere.*
> *(United Nations Development Program, 1995)*

Overview
Poverty exists as a cycle. The occurrence of poverty in one social, cultural, or economic dimension tends to affect other dimensions such as health or income investment. The less income a person, community, or country has, the less capital they have to reduce poverty over time (Lynn, 2005). Poverty, particularly persistent poverty, in rural America is greater than in urban areas (Weber, 2007). Many rural residents have been left behind or shut out of our nation's prosperity. Regionally, rural and small town poverty rates are highest in the South and lowest in the Northeast and Midwest. Too often poverty has the most detrimental impact on people who are the most vulnerable, overwhelmingly children, older adults, and people with disabilities (Housing Assistance Council, 2012). Even during good economic times in America, rural communities have experienced disproportionate poverty rates, with persistent poverty being more prevalent among more remote counties and areas with distinctive concentrations of racial/ethnic minorities (Weber, 2007).

The response to poverty in rural communities has been a combination of targeted governmental programs and policies, yet poverty persists. Edelman (2006) discussed the lessons we have learned from the "war on poverty" and identified lessons for future programs. Among these lessons were that poverty cannot be addressed successfully without addressing the question of income and rural poverty cannot be addressed in a vacuum.

The situation for people with disabilitiesis particularly dire, with over one in five persons with a disability living in poverty (21.5%) compared to slightly more than one in ten of those without (12.5%). The situation is even worse when one focuses on the working-age population (ages 21–64) where 28.1% of those with a disability live in poverty compared with 12.2% of those of working age without a disability (Erickson, Lee & von Schrader, 2016). Given that people with disabilities may have greater financial burdens due to their disabilities or health conditions, the implications for living in poverty may be even greater than these numbers would suggest.

Learning Objectives
By the end of the chapter, the reader should be able to:

- Understand how poverty is officially measured and the potential limitations and implications of the measurements used

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W.A. Erickson (✉) • S. VanLooy • S. von Schrader
S.M. Bruyère
K. Lisa Yang and Hock E. Tan Institute on Employment and Disability, Cornell University, Ithaca, NY, USA
e-mail: wae1@cornell.edu; sav22@cornell.edu; sv282@cornell.edu; smb23@cornell.edu

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- Understand the extent and significance of income inequality and the disability poverty gap in rural areas
- Be able to identify factors that may be related to the high poverty rates among the rural population with disabilities
- Become familiar with poverty alleviation/elimination policies and initiatives to date and their perceived outcomes and impact
- Understand the implications of poverty factors on the functioning of human service and vocational rehabilitation agency service administration and practice in rural areas, as well as on professional preparation and related research

Introduction

The interactions between disability and poverty are complex, and relatively little research exists that is specific to rural areas in the USA. Working-age individuals with disabilities in the USA are 2.3 times more likely to be living in poverty than their nondisabled peers (Erickson et al., 2016). Likewise individuals living in rural areas are more likely to live in households that live below the poverty line (US Department of Agriculture, 2014). Individuals with disabilities who live in rural areas may be doubly disadvantaged. In this chapter we provide a description of how poverty is defined in US policy, a broad overview of federal and state antipoverty public policy, and statistics describing the current status of people with and without disabilities with regard to poverty and economic well-being, as well as factors that may be related to the high poverty rates among the rural population with disabilities. Specific statistics about disability prevalence, economic conditions, and factors that may differentially impact the economic opportunities of individuals with disabilities in rural areas are presented. This information is a critical first step to understand income inequality and the disability poverty gap in rural areas, and to design policy to address issues specific to rural areas. Subsequent chapters will expand on this overview with chapters targeting barriers to reducing poverty in rural areas, specifically as they may differentially impact individuals with disabilities.

Theories of Rural Poverty

The majority of the world's poor live in rural areas, and a greater percentage of the population is poor in rural areas of the world (Dwyer & Sanchez, 2016). Rural poverty's causes are diverse, but many are rooted in a combination of economic underdevelopment, decline, or neglect. The rural economy is largely concerned with food and commodity production rather than emerging technologies and industries, and the lack of diverse opportunities leads younger and more educated residents to migrate away (Dwyer & Sanchez, 2016).

It is widely understood that poverty is linked to geographical disparities and that some communities and locations lack the resources to improve the well-being of their population (Bradshaw, 2006; Dwyer & Sanchez, 2016). It has been observed that economic resources tend to cluster or aggregate together – successful businesses attract more businesses, pulling resources away from other communities, while communities left behind experience economic restructuring and delays in receiving new technologies (Bradshaw, 2006).

Studies of poverty, however, particularly studies of poverty in the USA, have largely focused on the issue of urban poverty. "The American public generally perceives poverty as an urban problem" (Dudenhefer, 1993). Rural poverty has been considered a logical outcome of rural work culture, a lack of skills and preparation on the part of rural workers, and a lack of rural human capital. However, the 1990 Task Force on Persistent Rural Poverty suggested a reframing of these assumptions, stating that the changing nature of the rural economy since the end of World War II has created a fundamental problem: low wages and inadequate opportunities for youth, minorities, women, and the least educated (Dudenhefer, 1993). These changes have resulted from the restructuring of US manufacturing base, the growing influence of resource-extraction firms in rural areas, and the privatization of management of rural lands.

US Antipoverty Public Policy

The US dialog on poverty over the last few decades has been framed in terms of welfare policies rather than poverty itself, such that poverty has come to be discussed largely in terms of what benefits the poor receive, rather than the underlying social structures that put people on the benefit rolls (Edelman, 2009). Edelman (2009) suggests that the national debate on poverty since the 1980s has not been about addressing its causes but about blaming its victims.

This perspective on poverty puts the USA at odds with most other "wealthy" nations. The USA has higher poverty rates than most rich nations, spends less on antipoverty programs than most other rich nations, and defines poverty at a much lower threshold. It spends less on public programs and more on private social expenditures, and the money it does spend has a markedly smaller effect in reducing poverty than does similar amounts spent in European Union nations (Caminada & Martin, 2011; Smeeding, 2008). Most of these other nations also invest heavily in preventing childhood poverty in particular, due to clear evidence that child poverty is a significant risk factor for adult health conditions and disability (Racine, 2016; Smeeding & Thevenot, 2016). These differences are rooted in long-standing social and economic issues, including attitudes toward the poor, notions of social and personal responsibility, and attitudes about race (Caminada & Martin, 2011; Edelman, 2009; Martin & Caminada, 2011; Sachs, 2016).

Ways That Poverty Has Been Defined in US Public Policy

In January 1964, President Lyndon B. Johnson declared a "War on Poverty," introducing initiatives intended to "replace despair with opportunity" and improve the education, health, skills, jobs, and access to resources of the poor (Council of Economic Advisors, 2014). In 1969, the federal government set an official measure of poverty for these programs that was based on the cost of food (Fisher, 1992).

Currently, the US Census Bureau sets the "poverty threshold" with a formula based on "the cost of a minimum food diet … updated annually for inflation" (Institute for Research on Poverty, 2014b). This measure was first determined by economist and statistician Mollie Orshansky in 1963, using a list of foods then commonly considered acceptable and necessary, and was based on the assumption that food expenditures accounted for about one-third of a typical family's overall income (Fisher, 1992). That assumption was in turn based on a 1955 USDA Household Food Consumption Survey (Fisher, 1992). The cost of food used in this calculation was drawn from the USDA's "Economy Food Plan," which was created in 1961 as a food plan for short-term or emergency use, a lower step even than their "Low-Cost Food Plan."

Thus, the "poverty level" is based on a number of assumptions rooted in the 1950s and 1960s, reflecting situations that may not still exist today. The "Thrifty Food Plan" (the 1975 replacement for the "Economy Food Plan") has been criticized as including impractical and no-longer-realistic foods, as lacking the variety called for in updated dietary guidelines issued by the government, and as having unrealistic expectations regarding the availability of food and the facilities and time for food preparation (Food Research and Action Center, 2012). The poverty level calculations do not take into account the changing structure of the economy, including the decline in food costs as a proportion of overall expenses and the rapid rise in the cost of housing. It also does not reflect changed expenses including taxes, work expenses, childcare costs, or resources such as the availability of some in-kind benefits (Institute for Research on Poverty, 2014a). Others observe that income and consumption are not strongly correlated, and a consumption measure better reflects the desire to reduce material deprivation (Meyer & Sullivan, 2012; U.S. House of Representatives, 2014). Orshansky herself knew her measure was flawed from the start, believing that it understated poverty. She stated in the *Social Security Administration Bulletin* in 1965, "if it is not possible to state unequivocally how much is enough, it should be possible to assert with confidence how much, on an average, is too little" (Council of Economic Advisors, 2014, p. 9).

In response to these concerns, the US Census Bureau introduced the Supplemental Poverty Measure (SPM) in 2010. The measure is intended to "Provide an alternative view of poverty in the United States that better reflects life in the 21st century" (Institute for Research on Poverty, 2014a). It takes into account the costs of owning vs. renting homes, as well as a wide array of necessary expenditures, including medical costs, and the definition of minimum needs is adjusted each year based on recent data (Council of Economic Advisors, 2014). The measure is supplemental, however, and has not replaced the official poverty measure for use in government programs and means-tested benefit eligibility. However, SPM indicates even greater differences in poverty rates between individuals with and without disabilities; that is, the percentage point difference between individuals without disability and with disabilities is larger (Brucker, Mitra, Chaitoo, & Mauro, 2015).

Multidimensional poverty measures that focus beyond income on well-being may be even more relevant. These more complex measures may include dimensions such as "education, employment, economic resources and expenditures (including food security), health and heath care, political participation, and social inclusion" (Brucker, Mitra, et al., 2015, p. 274) and demonstrate even greater poverty for individuals with disabilities relative to nondisabled peers. Attempts to construct such measures, which reflect the links between income poverty, material hardship, and health, have confirmed that income-only measures underestimate the extent to which families experience economic disadvantage (Neckerman, Garfinkel, Teitler, Waldfogel, & Wimer, 2016).

Rural areas tend to have higher rates of poverty than metro areas, but the differences have decreased significantly over the last 45 years. When poverty rates are adjusted for different housing costs in metro and rural areas, poverty rates are actually higher in metro areas (Council of Economic Advisors, 2014). The cost of living in a rural region tends to be lower than in urban areas, largely due to lower food and housing costs (Arnold, Crowley, Bravve, Brundage, & Biddlecombe, 2014; Kurre, 2003; Nord, 2000). Methods of calculating cost of living, however, may underestimate actual costs for important areas of the country and do not take into account that nonhousing costs tend to rise with decreases in housing costs (Nord, 2000).

Despite overall lower costs of living, extreme poverty remains an issue in rural counties identified as "persistently poor" (high levels of poverty for over 30 years); 85% are rural counties. Since the Great Recession, rural counties have not seen as much employment growth as urban counties, although there are exceptions in areas with employment in oil and gas extraction (US Department of Agriculture, 2014). Our subsequent presentation of data that examines disability, income, and poverty by geographic region and rural area status sheds light on factors that may help to explain disparities and how to alleviate them. However, first we provide an overview of approaches to combat poverty at the national, state, and more local levels.

National Approaches to Poverty Alleviation

The leading federal antipoverty programs (in terms of expenditures) are the Earned Income Tax Credit (EITC) and the Supplemental Nutrition Assistance Program (SNAP) (Kearney & Harris, 2014). Other federal programs include Social Security (SSI and SSDI), unemployment insurance, housing subsidies, the national school lunch program, Temporary Assistance for Needy Families (TANF), and Women, Infants, and Children (WIC) nutrition support. Some of these programs are entirely administered at the federal level, in the form of federal benefits or federal tax credits, while others are administered via block grants to individual states (Council of Economic Advisors, 2014).

The federal safety net kept 41 million people above the poverty line in 2012, including 9 million children (Center on Budget and Policy Priorities, 2014, sec 3). The single most effective safety-net program is Social Security's provision of assistance to the elderly, people with disabilities, and the surviving spouses and children of workers. In 2012, Social Security reduced the overall poverty rate by 8.5 percentage points and lifted 26.6 million people above the poverty line, including 17 million senior citizens and 1 million children (Center on Budget and Policy Priorities, 2014; Council of Economic Advisors, 2014, sec 3).

The two largest safety-net programs by expenditure outlay, the Earned Income Tax Credit (EITC) and the Supplemental Nutrition Assistance Program (SNAP), are generally regarded by poverty scholars as effective (Kearney & Harris, 2014). SNAP in particular has proven to respond to economic conditions as a true safety-net program, with caseloads rising during downturns and falling during recoveries. Further, its long-term benefits to low-income children have been well-documented (Center on Budget and Policy Priorities, 2014; Kearney & Harris, 2014). Likewise, the EITC has been shown to boost employment among parents and increase their earnings by 17%, and is the most important factor in increasing employment among single mothers. In addition, children in families receiving EITC do better in school, are more likely to attend college, and have higher earnings as adults (Center on Budget and Policy Priorities, 2014, sec 3).

These programs are extremely important in the context of disability. Three-quarters of all low-income working-age people with disabilities participate in one or more of these safety-net programs, with public healthcare programs being the largest non-disability program category. Over half (52%) of people with disabilities aged 25–61 accessed at least one public health insurance program, compared to only 8% of people without disabilities (Houtenville & Brucker, 2014).

State and County/Local Government Approaches

While much of the funding for antipoverty programs comes from the federal government, many policies are now set at the state level. Welfare reforms of the 1990s gave states broad power to experiment with different approaches to delivering programs (Stanford Center on Poverty and Inequality, 2015), and many states have initiated their own programs and tax credits to support low-income workers (Weber, 2007). In turn, many of the most populous states shifted direct administration of these welfare programs to counties, giving counties new responsibilities for workforce development and poverty alleviation efforts (Lobao, Jeanty, Partridge, & Kraybill, 2012).

States have taken different paths in this area, with differing outcomes, attempting to balance the desire to encourage self-sufficiency with the need to prevent poverty. In general most states have chosen to either offer higher levels of benefits that taper off quickly as family income increases or to provide much lower levels of assistance to the very poor, but to continue to provide support to low-income workers (Stanford Center, 2015).

State and local approaches reflect the importance of local context in understanding poverty. As Weber (2007) states, “Local economic conditions matter” (p. 49). Local job growth is vital to moving people out of poverty, and community social capital is also a key component. Communities with greater civic participation and organizational membership also have seen greater poverty reduction (Weber, 2007). These observations echo those of Stauber (2001) who concluded, “Communities that survive and prosper also invest in building the social and human capital of their institutions and people. But communities with high social and human capital and declining economic opportunity are not likely to have positive futures” (p. 44).

The question remains, however, as to how effective local government responses to poverty have been. Lobao et al. (2012) analyzed the degree to which county government capacities and policies correlated with economic indicators. Counties are a good unit of study for this; they contain more residents than municipalities and are the fastest-growing general type of government. They provide more services such as welfare, health, and housing than cities do, and they raise more of the funds to do so themselves.

Despite this, county governments are rarely studied in this context and are often seen as barriers to poverty alleviation because of their tendency to adopt "race to the bottom" strategies in an effort to pursue growth at the expense of social welfare, accepting the growth of low-wage industries in order to be able to claim that growth is happening at all (Lobao et al., 2012).

Counties can alleviate poverty by developing and using administrative capacity in order to enhance efficiencies when enacting policies and programs. Lobao et al. (2012) found that it is administrative capacities such as the existence of professionalized staff and centralized resources, much more than specific policies, which seem to promote job growth and reduce poverty. Popular policies intended to attract business had no statistical effect on residents' well-being, while programs designed to divert resources to local entrepreneurs failed to create growth and reduced poverty alleviation efforts. The counties that were the most successful at promoting job growth and reducing poverty levels in their study were the most centralized governments with the greatest fiscal autonomy.

Rural Poverty and Disability

The local aspect of poverty in the USA is very important when considering rural disability and poverty. County-level poverty rates are lowest in the suburbs and increase as counties become more rural, while persistent poverty is disproportionately found in rural areas (Weber, Jensen, Miller, Mosely, & Fisher, 2005). Tickamyer and Duncan (1990) state that rural poverty has historically been linked to limited opportunity structures in rural communities, and these limits have been exacerbated by modern economic restructuring. With the globalization of the labor market and the transition from a resource-production and manufacturing economy to a market of services and ideas, isolation and instability have increased. Weber et al.'s review of the rural poverty literature (2005) found that all types of studies they examined report some form of "rural effect," that is, economic and demographic differences do not fully explain the increased poverty levels of rural communities. They suggest, however, that all the studies have methodological concerns that have not been addressed and that quasi-experimental studies are especially needed.

Suggested causes for this concentration of poverty in rural settings vary, with some concluding that isolation from institutions such as schools and the labor market is a major factor, while others suggest that a persistent system of "haves" and "have nots" enforce long-term poverty by socially isolating the have nots and preventing access to the resources they need for economic participation (Weber et al., 2005). The quality and type of locally available jobs also plays a role (Stauber, 2001; Weber et al., 2005).

The study of poverty has historically been the study of urban poverty, while rural studies have been marginalized. Rural poverty is the domain of agriculture schools rather than sociology or economics departments (Gurley, 2015). While rural and urban poverty share a common root in the inability of individuals to find work that pays a living wage, many causal factors of poverty are worse in remote areas, which lack the diverse human capital, transportation efficiencies, and labor market opportunities of cities (Gurley, 2015).

Writing before the recent Great Recession, Stauber (2001) observed, "We are headed back to a rural America of the rich and the poor – of resorts and pockets of persistent poverty" (p. 33). He stated that rural policies tended to be products of a "one size fits all" approach, created without regard to sector issues and often poorly modified urban or national-level policies (p. 41). He sees this as a result of cultural changes in the social contract between the urban majority and the rural minority and argues for specific investments in rural communities that he believes will make a difference. Based on studies of successful rural communities, he states that critical factors for community investment include investment in infrastructure, a focus on entrepreneurship and growth, emphasis on inclusion in the community, and strong leadership. Further, rural communities that have overcome poverty are those with people and institutions that work effectively across class lines and avoid domination by economic and social elites. State strategies for reducing poverty in rural areas can include support for local economic development (see Chap. 1), building community capacity, rewarding work efforts through tax credits and child care subsidies, increasing work supports such as transportation (see Chap. 3) and childcare, and improving worker productivity through education and training (Weber, 2007).

Both rural residence and poverty are inextricably tied to health status and disability (Braithwaite & Mont, 2009; Elwan, 1999; Fremstad, 2009; von Reichert & Myers, 2014). Longitudinal studies have shown that people earning less than twice the poverty level had significantly higher risk of diabetes, arthritis, back pain, hypertension, and heart disease (Givon, 2016). Rural residence limits access to healthcare; patients must travel greater distances to see doctors and are more likely to encounter barriers such as lack of transportation, severe weather, or bad roads. Rural areas also have significantly fewer physicians and have less than half the number of specialists per 100,000 residents, as well as fewer dentists, while rural hospitals often struggle financially as they attempt to care for a large number of Medicaid and Medicare patients, for whom reimbursements often do not cover actual costs (Joint Economic Committee, 2014).

According to Newkirk and Damico (2014), residents of rural areas are less likely than urban residents to have employer-provided health insurance. Half of all rural workers work in industry categories in which less than 80% of workers are covered by employer-sponsored insurance. Yet as a result of state policy decisions, rural areas are much more likely to fall into the "coverage gap" in which the Medicaid Expansion has not been implemented – 65% of the rural population lives in states that are not expanding Medicaid, compared to 50% of residents of metropolitan areas. Burton, Lichter, Baker, and Eason (2013) reviewed the literature of poverty, inequality, and health in rural America and report a wide range of health disparities: rural residents were more likely to report poor health, and a variety of chronic disease including cardiovascular conditions and cancer. Rural obesity rates are significantly higher than those of urban residents, and they have higher rates of injuries and accidental fatalities. Rural residents have poor dental health and less access to reproductive health services, and there are significant mental health differences (see Chap. 26) (p. 1138).

Policies have been enacted to address these issues of healthcare access. The Critical Access Hospital Program allows hospitals in remote areas a higher reimbursement for Medicare services, to keep rural hospitals economically stable and prevent closures and further reductions in numbers of providers. In addition, National Health Service Corps awards scholarships and loan forgiveness to primary care providers who agree to practice in underserved areas (Joint Economic Committee, 2014).

In addition, the rural population is aging more rapidly than the population as whole, and there is greater out migration of younger people. A disproportionate share of older Americans live in rural areas (Glasgow & Brown, 2012), and a larger share of them are the "oldest old" (age 85 and older). Overall, the more rural an area is, the older its residents and with this comes increased levels of chronic illness and disability.

Another major disadvantage of people with disabilities in rural areas is in obtaining safe, clean, and affordable housing. In 2009, nearly one-third of all rural households were cost-burdened, meaning that more than 30% of household income was required to cover housing costs (Housing Assistance Council, 2011). The number of cost-burdened renter households in rural areas increased by over 10 percentage points between 2000 and 2010, driven by rising rents and stagnating wages. While housing does cost less in rural than in urban areas, household incomes are similarly lower (Arnold et al., 2014). Additionally housing stocks in rural areas provide other challenges; housing is older and more likely to be in poor condition (Duncan, 1994). Aging rural residents who become disabled may require expensive home improvements to address hazardous bathrooms, steep staircases, narrow doors, and dated electrical installations (Housing Assistance Council, 2014).

Documenting Disability Prevalence and the Economic Divide Across Urban, Rural, and Persistently Poor Rural Counties

Thus far in this chapter, we have discussed national, state, regional, and local public policy approaches to reduce poverty. Additional insight on policy development can be gained by examining specific issues, such as in this case rural poverty and disability. In the following section, we present some estimates to better understand disparities and the factors associated with rural poverty and disability, beginning with a description of our approach to obtaining these estimates from existing data sources.

Data Sources and Measures

There are very few data sources that can provide reasonable substate estimates for rural areas such as at the county level. Based on recommendations of the US Census Bureau and the US Department of Agriculture (USDA) Economic Research Service (ERS) regarding subnational rural poverty statistics (US Department of Agriculture, 2016), we use data from the US Census Bureau's American Community Survey (ACS) for the majority of the estimates presented in this chapter. The ACS is nationally representative and surveys over three million households annually as well as the population living in a sample of institutional facilities (i.e., nursing homes, correctional facilities) and noninstitutionalized facilities (i.e., college dorms, military barracks, etc.) (Erickson, 2012). The Census Bureau compiles ACS data over a period of 5 years to provide an adequate sample to develop a limited number of estimate tables for even the most sparsely populated areas such as rural counties. However, due to the limited number of topics covered by the Census Bureau county-level tables, we also performed analysis of the ACS Public Use Microdata Sample (PUMS) to examine other topics of interest in greater depth for this chapter. Because of Census Bureau data confidentiality concerns, only larger, more populous areas can be specifically identified in the PUMS data. To address this limitation, we focus our analysis on predominantly rural areas, those with 70% or more of the total population living in rural areas.

The other data source used in this chapter is Social Security Administration's (SSA) administrative data for which is also available at the county level and provides insight into the receipt of SSA old age, survivor, and disability insurance (OASDI) benefits. Generally individuals who receive OASDI benefits between the ages of 18 and 64 do so because of a disability.

Defining Disability

There is no single accepted definition of disability. Different definitions and disability questions may identify different populations with disabilities and result in larger or smaller prevalence estimates. The six questions that are used in the ACS to identify persons with disabilities are primarily aimed at identifying sensory, functional, and activity limitations (Brucker, Houtenville, & Lauer, 2015). Note that respondents to the ACS can report more than one disability type and that some disability questions are not asked of children. The "Disability" category used in this chapter includes persons who reported one or more of the individual disability types:

- *Hearing disability (asked of all ages)*: Is this person deaf or does he/she have serious difficulty hearing?
- *Visual disability (asked of all ages)*: Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?
- *Cognitive disability (asked of persons age 5 or older)*: Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?
- *Ambulatory disability (asked of persons age 5 or older)*: Does this person have serious difficulty walking or climbing stairs?
- Self-care disability (asked of persons age 5 or older): Does this person have difficulty dressing or bathing?

- *Independent living disability (asked of persons age 15 or older)*: Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?

Defining Rural Areas

There are a number of ways of defining and classifying urban and rural areas (Cromartie & Bucholtz, 2008; Enders, Seekins, Brandt, 2005, U.S. Department of Health and Human Services, 2015). Given the topics we are discussing in this chapter, it was decided to utilize the Urban-Rural Classification Scheme for Counties[1] developed by the CDC's National Center for Health Statistics (NCHS). The NCHS Urban-Rural Classification Scheme for Counties was specifically designed for their utility in examining health differences across the urban-rural continuum. Counties may appear to be rather large areas to work with; however, there are difficulties in developing reliable estimates for entities below that geographical level, especially for areas with sparse populations. Given that limitation, it was determined that counties were the smallest reasonable geographical entity to use in this chapter to examine disability prevalence, poverty, and employment-related issues using existing data from the US Census Bureau and SSA.

The NCHS Urban-Rural Classification Scheme begins with the US Office of Management and Budget (OMB) metropolitan and nonmetropolitan categories, based on US Census Bureau population data. The OMB identifies metro counties as those containing one or more urbanized areas, including both high-density urban areas containing 50,000 people or more and outlying counties that are economically tied to the central counties (as measured by the share of workers commuting on a daily basis to the central counties). These counties are referred to as "urban" in the remainder of this chapter. Nonmetro (rural) counties lie outside the boundaries of metro areas and contain no cities with 50,000 residents or more. NCHS then further divides these basic categories into a six-part county classification comprised of four metro (urban) and two nonmetro (rural) groupings (Ingram & Franco, 2013).

For the purposes of analysis in this chapter, we combine the six classifications into four categories, focusing primarily on the two rural "size" categories: micropolitan and noncore counties (which can be thought of as the most "rural"). The 2013 NCHS Urban-Rural Classification Scheme includes 1167 metropolitan (urban) counties and 1976 nonmetropolitan (rural) counties. Nearly one in five Americans live in rural counties, and these counties comprise approximately 75% of the US land mass.

We further separate and examine the characteristics and economic situation of individuals living in the 301 "persistently poor" rural counties to provide a more detailed examination of these economically marginalized counties. Note that "persistently poor" rural counties are excluded from the micropolitan and noncore rural county estimates that are presented below.

Figure 2.1 shows the distribution of counties in the USA across the following four categories:

- Urban (1167 counties): metropolitan counties containing one or more urban core of 50,000 or more people. Less populous counties with close commuting ties may also be categorized as urban.
- Micropolitan rural (564 counties): rural counties with an urban core of 10,000–50,000 people. Excludes rural counties experiencing persistent poverty.
- Noncore rural (1111 counties): rural counties with an urban core population of less than 10,000. Excludes rural counties experiencing persistent poverty.
- Rural counties with persistent poverty (n = 301: 77 micropolitan and 224 noncore): includes all rural counties that have been identified as experiencing persistent poverty.

As can be seen, the vast majority of the US landmass is rural with the majority of the urban

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[1] Note that counties also include county "equivalents," 3141 total, and include 3007 entities called "counties," 16 boroughs and 11 census areas in Alaska, 64 parishes in Louisiana, and 42 independent cities (1 in Maryland, 1 in Missouri, 1 in Nevada, and the remainder in Virginia) and the District of Columbia.

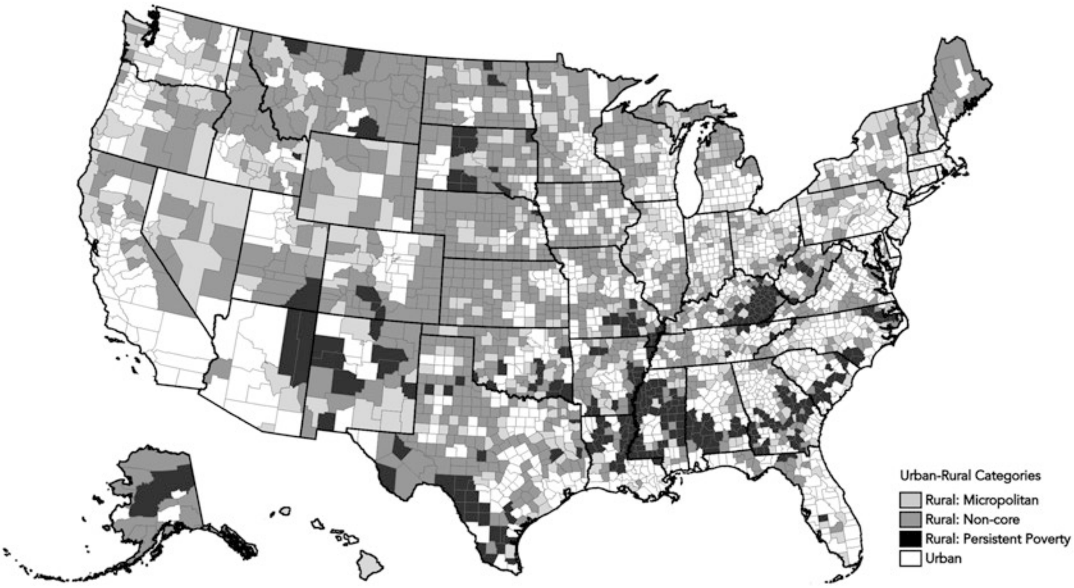

Fig. 2.1 US county map identified as urban, rural, micropolitan, noncore, and persistently poor (Data sources: adapted from Ingram and Franco (2013). Persistent poverty counties: http://www.ers.usda.gov/dataFiles/County_Typology_Codes/PersistentPovertyCounties.xls. Map produced by Michael Ward)

counties located along the coastal areas. There are a number of persistent poverty hot spots located in southern Appalachia and in the Deep South including the states of Alabama, Louisiana, Arkansas, and Missouri. Large swaths of central and western US counties are either rural noncore or micropolitan with a number of states comprised almost entirely of rural counties.

Disability Prevalence

Table 2.1 presents disability prevalence aggregated at the county level into the four county groupings: (1) urban counties, (2) micropolitan rural counties, (3) noncore rural counties, and (4) rural counties with persistent poverty. Disability prevalence is consistently higher in rural areas, with an average across counties of 15.2% for micropolitan counties, 16.4% in noncore rural counties, and 20% in the persistently poor rural counties, compared to 13.7% in urban counties.

As with overall prevalence, the prevalence of nearly every disability type is lowest in urban counties and increases from micropolitan to noncore and is highest in the persistently poor counties. This can clearly be seen in the maps provided in Figs. 2.1 and 2.2. There is a distinct cluster of about two-dozen persistently poor rural counties in the southern Appalachia region around the intersection of three states: Kentucky, Virginia, and West Virginia that is visible in Fig. 2.1. That same area also has some of the highest disability prevalence rates as well.

This same pattern of higher prevalence rates in the more rural areas holds for males, females, and each race grouping (see Table 2.1). Further, disability prevalence also varies greatly by age group. In the rural persistently poor counties, nearly one in five (18.6%) working-age individuals (18–64) reports a disability. Nearly 40% of individuals ages 65 and older have a disability in the urban, micropolitan, and noncore county categories; however, the highest prevalence rate (nearly 50%) is seen in the rural persistently poor counties. Clearly, across nearly all breakdowns presented, the prevalence of disability is higher in rural areas; however, prevalence rate is not all of the story. How do these individuals with disabilities actually fare in rural areas? In the next section,

Table 2.1 Average disability prevalence across urban and rural counties

		Rural		
Characteristics	Urban ($n = 1167$) (%)	Micropolitan ($n = 564$) (%)	Noncore ($n = 1115$) (%)	Persistent poverty ($n = 301$) (%)
Disability prevalence	13.7	15.2	16.4	20.0
Disability type				
Hearing	4.0	4.8	5.8	5.7
Visual	2.4	2.7	3.0	4.7
Cognitive	5.4	5.8	5.8	8.2
Ambulatory	7.8	8.6	9.4	12.6
Self-care	2.8	3.0	3.2	4.5
Independent living	6.2	6.5	6.7	9.7
Sex				
Male	13.8	15.4	17.1	20.3
Female	13.7	14.9	15.8	19.6
Race				
White	13.9	15.4	16.4	20.4
Black	14.9	15.1	19.1	21.4
Asian	6.8	7.8	8.5	10.0
Other race	11.7	13.3	16.1	18.4
Age				
Age < 5	0.9	1.0	1.0	1.0
Ages 5–17	5.8	6.1	5.9	7.0
Ages18–64	11.8	13.1	13.6	18.6
Age greater than 64	37.3	38.6	39.3	48.0

Note: Counties are the unit of analysis. Estimates include only civilian, noninstitutionalized population
Data source: Based on US Census table, S1810 disability characteristics, 2010–2014 American community survey 5-year estimates

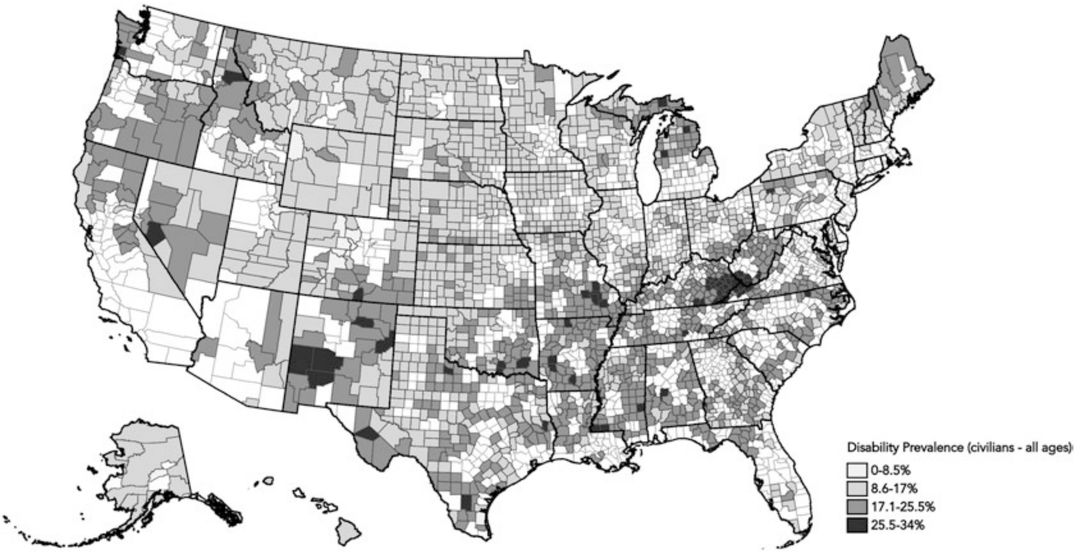

Fig. 2.2 Disability prevalence in rural counties (Note: Data for urban counties is not included. Urban counties are left unshaded. Data source: Based on US Census table, S1810 disability characteristics, 2010–2014 American community survey 5-year estimates. Map produced by Michael Ward)

we examine various indicators of economic well-being by disability status across these same county groups to explore this question.

Employment, Income Disparities, and Poverty Rate by Disability Status

Urban and rural micropolitan and noncore counties have similar employment rates for persons without a disability – around 75%. The employment rates for working-age (18–64) persons with disabilities are far lower, around 35–37%. Table 2.2 presents employment rate, median earnings, and poverty rate by urban and rural counties, again breaking down the rural counties into the three categories. Persons with disabilities are employed at only about half the rate of persons without as reflected in the employment rate ratios ranging from 0.46 to 0.49.

The employment situation in persistently poor rural counties is far worse than the other areas, with only 64.4% of persons without disabilities employed and less than a quarter of those with a disability, resulting in a 0.38 employment rate ratio. Not surprisingly, median earnings are slightly higher in urban counties, where the cost of living may be higher. Differences between individuals with and without disabilities are relatively consistent, with a typical individual with a disability earning only around 70% (0.70 earnings ratio) the amount of a typical person without a disability.

As discussed earlier in this chapter, the official poverty measure used in government programs and means-tested benefit eligibility has some

Table 2.2 Employment, earnings, poverty, and OASDI receipt by urban and rural county categories

Measure	Urban (*n* = 1167)	Rural Micropolitan (*n* = 564)	Noncore (*n* = 1115)	Persistent poverty (*n* = 301)
Employment rate (ages 18–64)[a]				
No disability	74.3%	74.4%	75.5%	64.4%
With disability	34.7%	35.3%	37.1%	24.3%
Employment rate ratio	0.46	0.47	0.49	0.38
Median earnings (workers ages 16+ with earnings in the past 12 months)[b]				
No disability	$30,817	$27,233	$27,074	$23,453
With disability	$21,103	$18,697	$19,317	$17,840
Median difference	$ 9700	$ 8512	$ 7738	$ 5613
Median earnings ratio	0.70	0.71	0.73	0.78
Poverty rate (ages 18–64)[c]				
No disability	12.6%	14.1%	13.0%	23.3%
With disability	26.4%	28.3%	26.6%	37.1%
Poverty rate ratio	2.28	2.16	2.23	1.65
OASDI receipt (ages 18–64)[d]	2.6%	3.0%	2.9%	6.6%

Numerator: Number of recipients in state (by eligibility category, age, and receipt of OASDI benefits) and amount of payments, by county, December 2014 (persons ages 18–64) https://www.ssa.gov/policy/docs/statcomps/ssi_sc/2014/table03alt.xlsx and denominator from U.S. Census table, S1810 disability characteristics, 2010–2014 American Community Survey 5-Year Estimates

Note: Counties are the unit of analysis. Estimates include only the civilian, noninstitutionalized population. Median difference and median earnings ratio are calculated using as the median of county differences and earnings ratios

Data sources:

[a] C18120 employment status by disability status. Universe: Civilian noninstitutionalized population 18–64 years 2010–2014 American Community Survey 5-Year Estimates

[b] B18140 median earnings in the past 12 months (in 2014 inflation-adjusted dollars) by disability status by sex for the civilian noninstitutionalized population 16 years and over with earnings. Universe: Civilian noninstitutionalized population 16 years and over with earnings in the past 12 months, 2010–2014 American Community Survey 5-Year Estimates

[c] C18130 age by disability status by poverty status. Universe: Civilian noninstitutionalized population for whom poverty status is determined 2010–2014 American Community Survey 5-Year Estimates

[d] Percentage derived based on SSA data: Table 3

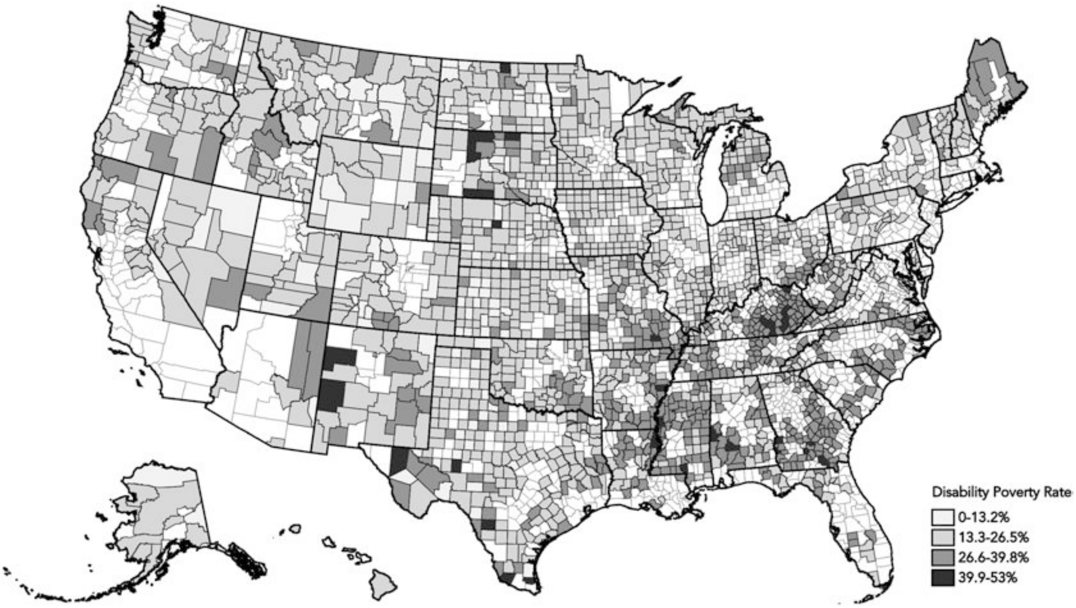

Fig. 2.3 Map of poverty rate for persons with disabilities of all ages in rural counties (Note: Data for urban counties is not included. Urban counties are left unshaded. Data source: Based on calculations on US Census table, C18130: Age by disability status by poverty status. Universe: Civilian noninstitutionalized population for whom poverty status is determined. Map produced by Michael Ward. 2010–2014 American Community Survey 5-Year Estimates)

serious limitations. However, given the fact that it is the measure used in most government programs, our discussion focuses on those official poverty measurement estimates. Individuals with disabilities in urban and rural micropolitan and noncore counties are over twice as likely (poverty rate ratio ranging 2.16–2.28) to be in poverty than their nondisabled peers, with over a quarter living below the poverty line. Again the situation for persons with disabilities living in persistently poor counties is far worse with over a third (37.1%) living in poverty.

It is interesting to note that the poverty rate ratio is actually lower for persistently poor counties at 1.65 times. This lower ratio is due to the much larger proportion of the comparison group, persons without disabilities, who are also impoverished. Persons ages 18–64 living in rural areas are slightly more likely to be receiving OASDI (disability) benefits than those living in urban counties, with rates ranging from 2.5% to 3.0%. However, working-age persons in the rural persistent poverty counties are over twice as likely to receive OASDI as those living elsewhere at 6.6%, or about one in 15 persons.

Figure 2.3 is a county-level map displaying poverty rates for individuals with disabilities for all rural counties and clearly shows the clustering of poverty. Again one of the most striking areas is in the southern Appalachian area, especially in the central Kentucky area with eight counties having nearly half of all persons with disabilities living below the poverty line and most of the remaining counties having over 25% poverty rates. Five rural counties in Georgia and five in South Dakota also have extremely high poverty rates with two out of five persons with disabilities living below the poverty line. More than one in four persons with disabilities are living in poverty in many rural counties located in the Deep South.

Related Factors: Educational Attainment, Employment, Age, Gender, and Race/Ethnicity

As noted above, data available from the Census Bureau county level tables at the county level is limited. The remainder of our tables use estimates from the ACS Public Use Microdata Sample (PUMS) to examine other topics of interest. Because of data limitation noted previously, the remainder of the analysis is on "predominantly rural areas," defined as those with 70% or more of the total population living in rural areas. Table 2.3 examines the situation of persons living in predominantly rural areas and their households by disability status. Note that although the differences are not unique to rural areas, the estimates provided serve to further develop a sense of barriers and issues that working-age persons with disabilities and their households who live in rural areas face.

Table 2.3 Person and household and level estimates of working-age (18–64) persons living in predominantly rural areas by disability status

	Disability	No disability
Person-level estimates		
Poverty	32.3%	15.2%
Health insurance	86.0%	81.1%
Public insurance	59.9%	14.1%
Private insurance	37.8%	70.1%
Education attainment		
Less than high school	25.1%	11.6%
High school	40.7%	36.5%
Some college	27.1%	34.2%
Bachelor's degree or higher	7.1%	17.7%
Employment rate	27.2%	72.4%
Type of employment (occupation)		
Management, business, science, and arts	23.0%	29.3%
Service	20.9%	17.6%
Sales and office	19.6%	21.7%
Natural resources, construction, and maintenance	14.9%	12.9%
Production, transportation, and material moving	21.6%	18.4%
Household-level estimates[*]		
Food stamps	35.1%	14.4%
Computer in house	75.5%	85.9%
Internet access	67.8%	77.9%
Median household income	$40,337	$63,530

Note: Predominantly rural areas are defined as Public Use Microdata Areas (PUMAs) with 70% or more of the population living in rural areas. Estimates based on analysis of the 2014 ACS PUMS data

[*] Households with one or more working-age (18–64) person(s). Disability: one or more working-age persons with a disability living in household. No disability: no working-age person with a disability in household

The poverty level of persons with disabilities living in predominantly rural areas is over twice that of persons without disabilities living in those areas. Although persons with disabilities are more likely to have health insurance, they are far less likely to have private health insurance than persons without disabilities. With regard to educational attainment, persons with a disability are much more likely to have less than a high school education than those without and less likely to have any postsecondary education. Only about one in four persons with disabilities are employed as compared to almost three out of four persons without disabilities. Of those that are working, many are employed in occupations that are typically lower paid relative to those without disabilities. Households with a working-age person with disability have a much lower median household income, a third less than households without working-age persons with a disability. Households with a working-age person with a disability were twice as likely to be receiving food stamps and much less likely to have a computer and Internet access.

Implications for Rehabilitation Counselors and Human Service Providers

Providing human and/or vocational rehabilitation services in rural America can be particularly challenging, as the array of issues presented in this book makes clear. In tracing poverty program development and implementation and its efficacy, this chapter has briefly discussed how provisions shaped at the federal and state level to address poverty may not translate readily or neatly to the local level, where antipoverty policy actually plays out in people's lives in ways that heavily depend on local job markets and social networks. Approaches commonly used in urban areas often do not successfully translate to rural catchments. For example, in urban areas, programs and shelters can provide short-term solutions to address homelessness, while the rural homelessness issue affects areas in which population density may well not be sufficient to make this a sustainable alternative. Similarly, where efficiencies of service delivery may be gained with block grant funding in urban areas, such an approach may make delivering services more expensive in rural areas.

The rural poverty and employment statistics presented in this chapter suggest that individuals with disabilities in rural areas are disproportionately impacted by the economic, employment, housing, transportation, and health disparities which are endemic in rural areas for the population at large. We will here discuss some of the specific issues around program design and service coordination and their implications for service program administration, as well as service practitioner pre-service training and ongoing professional development.

Poverty, disability, and income are inextricably linked, and any attempt to address them in rural America must take into account the array of needed services and resources to systemically address interrelated issues. Programs are often administered by several departments (e.g., Agriculture, Treasury, Health and Human Services, Labor, Housing and Urban Dev.), each with its own eligibility criteria. To be successful, service providers and community planners need to work together to create a more holistically sound and integrated approach to these problems. Economic development, workforce development, and housing, transportation, and community planning interests need to be aligned both in intervention strategy design and ultimate implementation. Consortiums of service administrators and on-the-ground providers across all of these interests must be coalesced, similar to the workforce development consortium models now required by the Workforce Innovation and Opportunity Act requirements.[2]

Throughout all of this, it is imperative that grassroots input be included in the design to assure the relevance and effectiveness of the structure of services. Such input can be gathered by in-person community forums, via surveys conducted online or by mail, or by other means of outreach that elicit meaningful responses to the needs assessment and service design process. Input gathered from across a variety of sources and constituencies is a vital part of the design of useful services and service delivery systems that will meet the most critical needs of citizens and create enduring longer-term impacts.

Administrators of vocational rehabilitation, health, and other human service delivery programs cannot simply impose the same service structures that work in urban areas, but rather must equip service providers with the necessary tools for effective service delivery in rural environments. As described above, the defining feature of a rural region is its low population density and lack of an urban core that would serve as a physical center for program delivery. Inhabitants of these areas are geographically dispersed, making it difficult to reach clients. Service system designers must also recognize that intended service recipients might not have the ability to get to centralized service delivery locations due to lack of a transportation infrastructure to serve low-income residents and the inability to pay for private transportation. While many agencies are increasingly using email and websites to enhance their service delivery options, households with working-age persons with disabilities in predominantly rural areas are far less likely to have computers or Internet access. This limits their ability to become knowledgeable about services via the Web, or be reached by email to solicit applications, arrange appointments, or provide follow-along updates. There may also possibly be unwillingness to participate as a result of lack

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[2] https://www.federalregister.gov/documents/2016/08/19/2016-15977/workforce-innovation-and-opportunity-act-joint-rule-for-unified-and-combined-state-plans-performance

of trust that governmental or service delivery structures will deliver if approached, due to past disappointing experiences.

Table 2.3 illustrates that the employment rate for both people with and without disabilities in rural counties is significantly lower than in urban areas. This has prompted a movement of younger population away from rural areas as they seek educational and job opportunities. As a result many people have lost the support of younger family or friends who could assist with transportation and communication concerns and provide social support and resources. At the same time, the consolidation of healthcare facilities and other services into metropolitan centers and the loss of healthcare and other providers at the local level means that the need for transportation and communication has increased.

Examples of service structures that can assist providers in dealing with these issues might be agency-sanctioned financial support of costs for the use of service provider mobile phones to reach clients or costs for transportation across large geographic areas to personally reach clients to establish relationships and directly deliver services. Also of importance, since time in the office will be less, is that caseload size reflects the time that service providers may need to travel to reach their clients. Service providers will need to be afforded the time to reach clients who will not be able to or will chose not to go into central location offices and may need face time to establish critical trust relationships which will heighten the likelihood of service uptake and follow-through.

Appropriate pre-service and post-service preparation of professionals to adequately equip them to work in rural areas is critical. Understanding differences in service delivery structures, availability of resources, and the importance of respect for and adaptability to local area norms and cultural differences is imperative. In a country that has such a large rural area, it would seem that these considerations in human service and vocational rehabilitation counselor training would be prevalent, but to date, they are not. Creating opportunities for learning about these differences in coursework and internship/practicum instructional experiences at the pre-service level in human service preparation is one part of addressing the gap in effective service delivery. Offering ongoing learning opportunities for the career development of professionals practicing in rural areas is also a necessary part of the quality service delivery equation. Having agencies and administrative infrastructures that recognize the importance of adequately prepared personnel and invest in professional development strategies that reach dispersed staff in a timely and cost-effective manner will be imperative. Creating complementary digital or e-communication structures and networks that afford dispersed staff an opportunity to do needed case consultation on particular issues and maintain a sense of team effort across distance will also be an important part of building a capable service delivery workforce which will be better prepared to provide high-quality services over time.

Summary

The focus in this chapter has been to discuss disability, income, and poverty using a review of related policy and poverty literature and to provide related statistics drawn from national survey and administrative data regarding the situation of persons with disabilities in rural areas. In addition, we discuss how the occurrence of poverty in one social, cultural, or economic dimension tends to interact with other dimensions such as income, health, or education investment. We described how poverty is defined in US policy and offered a broad overview of federal and state antipoverty public policy, statistics describing the current status of people with and without disabilities with regard to poverty and economic well-being, and factors that may be related to the high poverty rates among the rural population with disabilities.

We are focused on poverty and disability because the situation for persons with disabilities is particularly dire. Individuals with disabilities in the USA are 2.3 times more likely to be living in poverty than their nondisabled peers (Erickson et al., 2016). Specific statistics about disability prevalence, economic conditions, and factors that may differentially impact economic opportunities of individuals with disabilities in rural areas are a critical first step to understand income inequality and the disability poverty gap and to subsequently design policy which addresses issues specific to rural areas.

Rural poverty's causes are diverse, but many are rooted in a combination of economic decline, neglect, or underdevelopment. The rural economy has been rooted historically in agriculture rather than emerging technologies and related industries, and the lack of opportunities that these growth areas afforded in rural communities has meant that young people often move away, leaving a widening education, economic and healthcare gap for the aging residents, and an even higher preponderance of those with disabilities and without employment in these communities.

Rural poverty has been discussed largely in terms of what benefits the poor receive, rather than the underlying social structures that put people on the benefit rolls. It has been considered a result of rural work culture, a lack of skills and preparation on the part of rural workers, and a lack of rural human capital. Changes in both the way poverty is defined and measured and in the policies and structures designed to alleviate poverty need to be undertaken, with a contemporary perspective of underlying causes and possible solutions. For example, current poverty level calculations do not take into account the changing structure of the economy. Although the US Census Bureau introduced the Supplemental Poverty Measure (SPM) in 2010, this measure is supplemental and has not replaced the official poverty measure for use in government programs and means-tested benefit eligibility. More permanent modernized measurements need to be imbedded in current policy and intervention approaches.

A focus on providing solutions that do more than provide a safety net of benefits is imperative. It is crucial that both workforce and economic development strategies be a part of any intervention to better ensure the desired longer-term changes needed. Isolation from institutions such as schools and the labor market has been a major contributing factor to rural poverty, and people with disabilities have been even more significantly disadvantaged by these disparities. Addressing ways to raise educational and vocational skill development levels among citizens in rural communities is critical, especially for those with disabilities. In addition, injecting into these communities employment opportunities with jobs affording higher pay and longer-term career growth is essential.

To take advantage of any infusion of workforce and economic development opportunities, communities need to develop the necessary infrastructure to support these initiatives so that residents can realize the potential benefits that education and employment opportunities can provide. Adequate infrastructure for housing, transportation, and healthcare that are equitably accessible to all across economic and social class lines will be a necessary part of democratizing opportunity. Growth industries such as technology which afford high-paying jobs with career advancement opportunities may also offer creative new solutions whereby citizens can access work without leaving their communities. It is time that we identify solutions whereby both communities and individual citizens in rural America can not only survive economically but thrive and build a promising future. A more comprehensive approach to poverty elimination beyond the traditional social net services is long overdue.

Resources

Disability Statistics. http://www.disabilitystatistics.org/

Online source of national and state level reports and data presenting the prevalence of disability and relative economic status of people with disabilities, from a variety of large public datasets.

Rural Poverty Research Institute. http://www.rupri.org/

The Rural Policy Research Institute (RUPRI) provides unbiased analysis and information on the challenges, needs, and opportunities facing rural America. RUPRI's aim is to spur public dialog and help policymakers understand the rural impacts of public policies and programs.

The Housing Assistance Council. http://www.ruralhome.org/

A national nonprofit that helps local organizations build affordable homes. HAC also has developed a library of full-length research reports, research briefs, and other informational products that provide details and analysis on social, economic, and housing issues that affect the provision of affordable housing in rural America.

USDA ERS (US Department of Agriculture Economic Research Service). http://www.ers.usda.gov/topics/rural-economy-population/rural-poverty-well-being.aspx

ERS research focuses on the economic, social, spatial, and demographic factors that affect the income and poverty status of rural residents.

RHI Hub – the Rural Health Information Hub. https://www.ruralhealthinfo.org/topics/people-with-disabilities

The Rural Health Information Hub was formerly the Rural Assistance Center. It is funded by the Federal Office of Rural Health Policy as a national clearinghouse on rural health issues. It provides access to current and reliable resources and tools to help you learn about rural health needs and work to address them.

US Census Bureau American FactFinder. http://factfinder.census.gov/faces/nav/jsf/pages/index.xhtml

The Census Bureau's American Factfinder (AFF) website provides access to a wide variety of statistics, many based on the American Community Survey (ACS). AFF is a very useful source for poverty- and disability-related estimates especially for smaller, less populous areas including rural counties, villages, and cities as well as at the state and national level.

Instructional Features

Discussion Boxes

Discussion Box 2.1: Defining Disability

There is no single, universally accepted definition of disability. However, assessing the effectiveness of disability policy requires some measure of what disability is, and these different definitions affect our understanding of policy outcomes. Mashaw and Reno (1996) document over 20 definitions of disability used for purposes of entitlement to public or private income support programs, government services, or statistical analysis. Depending on the data sources used (and their disability definitions), estimates of disability prevalence and rates of employment and poverty can vary significantly.

The American Community Survey (ACS) uses a series of six questions that primarily focus on six specific functional or activity limitations. However, these six items do not capture everyone who might be considered to have a disability, such as those with mental illness or persons with upper body impairments, or other specific health conditions. The 2010 Survey of Income and Program Participation (SIPP) used a much broader definition of disability than the ACS and included many more items and conditions. For reference the 2010 ACS estimated that there were approximately 36.4 million persons of all ages with a disability (11.9% prevalence rate), whereas the 2010 SIPP estimates 56.7 million (18.7%).

Discussion Questions:

1. How might these different definitions affect the "official" number of people with disabilities?
2. What preconceived notions about disability are apparent from these definitions?
3. What might be some of the implications of using different definitions of disability? If they are broader? Narrower?

Discussion Box 2.2: Defining Poverty

The official US Government measure of poverty uses the US Census Bureau definition introduced in the 1960s, adjusted for inflation. This measure compares pretax cash income against a poverty threshold set at three times the cost of a minimum "grocery cart" of food.

Researchers have suggested that this measure has flaws: it does not reflect new expenses of living in modern society, it does not include sources of income such as noncash assistance, and it does not reflect the nature of twenty-first-century households. Others observe that the relationship between income, consumption, and possession of goods cannot be neatly specified.

The Census Bureau introduced the Supplemental Poverty Measure in 2010 to provide an alternative view of poverty that better reflects the twenty-first-century life. This measure supplements, but does not replace, the official poverty measure.

Many other countries use and suggested ways of measuring poverty include measurements of "relative" poverty, which express poverty in terms of relationship to the median income, or measurements of "material hardship," which track how difficult it is to acquire the housing, food, and medical care a family needs.

Proposed methods of measuring poverty can be described as "direct" methods, observing the lack of basic needs, and the "income" method, observing the flow of available cash. These methods are not just alternative measures, but alternative concepts of what poverty *is*.

Discussion Questions:

1. How has society changed since the introduction of the official poverty measure in 1963?
2. What differences might result from defining poverty based on income vs. defining it based on ability to meet household needs?
3. How might these definitions apply differently in rural areas vs. urban ones? In households composed of older individuals vs. households of predominantly younger people?

Research Box 2.1: See Iezzoni, Killeen, and O'Day (2006)

Objective or Research Question: To learn about the healthcare experiences of rural residents with disabilities.

Method: Interviews were conducted with 35 adults recruited from centers for independent living in rural Massachusetts and Virginia. Participants were people with sensory, physical, or psychiatric disabilities. Four focus groups were conducted.

Results: Interviewees confirmed experiencing many known barriers to accessing healthcare in rural America and reported that their disabilities made these barriers more difficult. Barriers included difficulty in finding healthcare practitioners well-versed in their disability, needing to educate practitioners about disability, difficulty finding medical practices that accept Medicaid and Medicare patients, and the need to travel long distances to regional medical centers in order to get specialty care. Physical access of healthcare facilities and access to transportation emerged as major concerns.

Conclusion: Improving healthcare access for rural people with disabilities requires not only ensuring availability of appropriately prepared healthcare practitioners but also addressing serious concerns around physical accessibility and transportation.

Questions:

1. What are some issues specific to healthcare providers that might be relevant to meeting the healthcare needs of people with disabilities in rural areas?
2. What are some non-healthcare issues that affect how people with disabilities might access healthcare in rural areas?

Research Box 2.2: See Neckerman et al. (2016)

Objective or Research Question: To better understand the links between income poverty, material hardship, and health.

Method: Researchers designed a survey, called the New York City Longitudinal Study of Wellbeing, or "Poverty Tracker," to gather data from approximately 2300 New York City residents on income poverty, material hardship, health, and well-being. Data was collected from the same sample over time, with interviews every 3 months over 2 years to provide a comprehensive picture of poverty and how it relates to material hardship and well-being. The tracker included not only the Census Bureau's new Supplemental Poverty Measure but also tracked the experience of hardship issues such as running out of money, utility cutoffs, food insecurity, unmet medical needs, and housing hardships. It also included an indicator of family health: whether the adult respondent reported a work-limiting disability or rated their own health as poor.

Results: Hardships were experienced more often by families that were also experiencing income poverty. Nearly half of families with children experienced "persistent" disadvantages over the survey period, and only one-third of families faced no hardships during that time. However, statistics on persistent poverty understate the level of sustained disadvantage – only 11% of families with children were "poor" at both time points.

Conclusion: Focusing on income poverty alone vastly underestimates the extent of disadvantage among families with children. Many families with incomes above the poverty line experience material hardship and/or health difficulties.

Questions:

1. This study used the presence of disability as a marker for family disadvantage. How might that affect attempts to study the relationship between poverty and disability?
2. This study took place in an urban setting. What additional or different factors might exist for families in rural areas that affect their experience of disadvantage?

Illustrative Case Study or Vignette or Profile of a Person with a Disability in a Rural Area

Bernice is a 37-year-old Black American woman with an intellectual disability living in Avera, GA. Bernice was born with Down syndrome, the last of 7 children in her family, and went to a special education class in the greater Jefferson County Unified School district up to the 8th grade. She left school before completing 8th grade, as her family wanted her to stay home to help with parental care. Her father was diabetic and had his leg amputated and had to leave his job as a janitor in the local school. The mother then had to become the family income earner and was driving to another town to work. Bernice was asked to stay at home with the father, who became increasingly ill and ultimately bed-ridden. Bernice's parents filed for Social Security Insurance benefits on Bernice's behalf and also became dependent on this as income to support the household as a whole. Both of Bernice's parents, now in their 70s, died in the past 18 months, and Bernice had been living alone as her siblings have all moved away in an effort to find employment. An aunt who lives nearby has occasionally been looking in after her but is concerned about Bernice's longer-term well-being and ability to support the costs of a household independently, as well live safely on her own over the longer term. The aunt made a referral for Bernice to both a local Social Service Agency and to vocational rehabilitation, to try to get help with finding a safe and affordable living place with supports and assistance for exploration of employment alternatives. As the rehabilitation counselor accepting this referral, how would you approach providing support to Bernice in this process? What vocational exploration approach might you use? What is your role in residential and transportation issues that Bernice might be confronted with? What involvement would you see the family having? What other considerations might there be in moving forward with providing Bernice to identify meaningful community engagement and as much independence as possible within this setting?

Learning Exercises
Self-Check Questions

1. Why is the issue of disability and poverty an important one to focus on?
2. What are the consequences of poverty for individuals with disabilities in rural areas?
3. What are the factors that contribute to a disproportionate impact of poverty in rural areas?
4. How would you characterize the public policy poverty programs for people with disabilities?
5. Do you think that these programs are effective? Which features of these programs are the most effective?
6. What are the implications of rural poverty and individuals with disabilities for the functioning of rehabilitation and other human services designed to support these populations in rural areas?

Field-Based Experiential Assignments

1. What is the prevalence rate of people with disabilities in your state or regional/local geographic area?
    - (a) Where would you go for information?
    - (b) What geographic catchment area is viable and why?
    - (c) How do these rates compare with national prevalence rates for this group?
2. What is the employment rate of individuals with disabilities in this state/regional or local catchment area?
    - (a) How does that rate compare with people without disabilities in the same catchment area?
    - (b) How does that participation rate compare to people without disabilities nationally?
3. What are the household income and poverty rates of individuals with disabilities in your state/regional/local area?
    - (a) How are individuals with disabilities in rural areas of this catchment area faring in terms of comparative household income with their nondisabled peers?
    - (b) How are individuals with disabilities in rural areas of this catchment area faring in terms of poverty rates with their nondisabled peers?

Multiple-Choice Questions

1. The poverty rate for working-age Americans with disabilities compared to their nondisabled peers is:
    - (a) Approximately five times higher
    - (b) Relatively the same rate
    - (c) Over twice the rate
    - (d) Significantly less than individuals without disabilities
2. Which of the following statements about poverty is false?
    - (a) It is a function of poorly planned and implemented economic development.
    - (b) The majority of the world's poor live in rural areas.
    - (c) A greater percentage of the population is poor in rural areas.
    - (d) The rural economy is largely concerned with food and commodity production.
3. Low wages and inadequate opportunities for youth, minorities, women, and the least educated are a result of:
    - (a) The restructuring of US manufacturing base
    - (b) The growing influence of resource-extraction firms in rural areas
    - (c) The privatization of management of rural lands
    - (d) All of the above
4. Compared to other wealthy nations globally, which of the following is true about the US situation related to poverty?

   (a) The USA spends more on antipoverty programs than most other rich nations.
   (b) The USA has higher poverty rates than most rich nations.
   (c) The USA defines poverty at a much higher threshold.
   (d) The USA spends more on public programs and less on private social expenditures.
5. Which of the following is true of the Supplemental Nutrition Assistance Program (SNAP)?
   (a) It is generally regarded as an effective US poverty alleviation policy program.
   (b) It is generally regarded as an ineffective US poverty alleviation policy program.
   (c) Its long-term benefits to low-income children have not been well documented.
   (d) It has not proven to respond to economic conditions as a true safety-net program.
6. Which of the following is *not* true about the Supplemental Poverty Measure (SPM)?
   (a) SPM indicates even greater differences in poverty rates between individuals with and without disabilities.
   (b) The measure has replaced the official poverty measure for use in government programs and means-tested benefit eligibility.
   (c) It takes into account the costs of owning vs. renting homes, as well as a wide array of necessary expenditures.
   (d) The definition of minimum needs is adjusted each year based on recent data.
7. Which of the following is true of county governments in the USA?
   (a) They are the fastest-growing general type of government.
   (b) They provide more services such as welfare, health, and housing than cities do.
   (c) They raise more of the funds themselves to address service needs.
   (d) All of the above.
8. Which of the following is *not* true about access to healthcare in rural areas?
   (a) Patients must travel greater distances to see doctors.
   (b) Medicaid and Medicare reimbursements to hospitals in rural areas appropriately cover the actual costs of care provided for these patients.
   (c) Patients are more likely to encounter barriers such as lack of transportation, severe weather, or bad roads.
   (d) There are significantly fewer physicians, specialists, and dentists.
9. Which of the following is *not* generally true of people with disabilities in rural areas?
   (a) Prevalence of disability is greater in rural areas.
   (b) The employment rate of people with disabilities is significantly less than those without disabilities.
   (c) A greater proportion of people with disabilities have private health insurance than public health insurance.
   (d) The poverty rates of people with disabilities are greater than those without.
10. Some ways of helping human and rehabilitation service providers be better equipped to provide quality services in rural areas are to:
   (a) Afford access to needed equipment (cell phones) and transportation support to readily reach clients who are dispersed throughout a large geographic area
   (b) Assign caseload sizes that take into account the requirements for significant out-of-office time to travel to outreach to service recipients and provide services
   (c) Provide a communication infrastructure for practitioners that enables case consultation and team coordination across a geographically dispersed area
   (d) All of the above

Key

1 – C
2 – A
3 – D
4 – B
5 – A
6 –B
7 – D
8 – B
9 – C
10 – D

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3

Transportation, Accessibility, and Accommodation in Rural Communities

Bradley W. McDaniels, Debra A. Harley,
and David T. Beach

Overview

Transportation symbolizes mobility and the ability to have access to services, health care, work, school, shopping, and entertainment and social venues. In rural, frontier, and territory (RFT) communities, as well as in small urban towns, transportation consists primarily of personal vehicles because these areas do not have the transportation infrastructure as larger areas (American Public Transportation Association, 2012). However, nearly 6% of rural households and more than 6% of small urban households do not have access to private vehicles (U.S. Department of Transportation & Federal Highway Administration, 2011). A continual distinction of rural areas from small urban towns is that transportation expansion is still disproportionately unavailable for RFT communities. The need for transportation in RFT communities cannot be understated. This is particularly true for older residents, for as people age so too does the need to be able to access health care. Approximately 21% of Americans over the age of 65 do not drive; thus, access to transportation is critically important for older adults in RFT communities (Lynott & Figueiredo, 2011). Although the percentage of women drivers age 65 and older is increasing, older men continue to drive more than women of the same age, and, on average, men age 65+ drive twice as many miles as women (Lynott & Figueiredo, 2011). See Chap. 11 for further discussion on the elderly in RFT communities. In the USA, only 32% of all rural counties have full access to public transportation services, and 28% have limited access, leaving 40% of rural residents with no public transit options at all (Brown & Stommes, 2004). For rural residents living near or below the poverty level, limited transportation options isolate and restrict access to government services and programs designed to assist them (Criden, 2008; Shoup & Home, 2010).

Access to transportation in rural communities in general, and public transportation, in particular, offers residents numerous benefits, including (a) lower household expenses due to freeing up of income for other uses, (b) reduced social and economic inequalities through enhanced mobility for residents, (c) improved economic efficiency by allowing unemployed individuals to have a means to find and keep a job, and (d) preservation of rural communities and sustaining of their character (Criden, 2008). Although these benefits apply to all residents in RFT communities, for those with disabilities, these benefits can often mean the difference in independence and self-determination.

B.W. McDaniels (✉) • D.A. Harley • D.T. Beach
Department of Early Childhood, Special Education,
and Rehabilitation Counseling, University of Kentucky,
Lexington, KY, USA
e-mail: bradley.mcdaniels@uky.edu

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Learning Objectives

By the end of the chapter, the reader should be able to:

1. Identify transportation challenges in rural communities.
2. Distinguish the extent of transportation challenges for various types of rural regions.
3. Understand federal transportation policy and programs regarding transportation accessibility and accommodation for persons with disabilities.
4. Compare and contrast models of rural transportation.

Introduction

Rural, frontier, and territory areas are defined primarily by population density, geographic characteristics, and distance between residents. The Dye Management Group (2001) describes three types of rural areas. First, *basic rural* areas are dispersed counties or regions with few or no major population centers of 5000 or more that are mainly characterized by agricultural and natural resource-based economies, stable or declining populations, and "farm-to-market" localized transportation patterns. Second, *developed rural* areas are dispersed counties or regions with one or more population centers of 5000 or more, economies tend to be mixed industrial and service based in the cities and agricultural and natural resource based in the rural areas, with populations that are stable and growing, and more diverse transportation (i.e., commuting, intercity travel/freight). Third, *urban boundary rural* areas are counties or regions that border metropolitan areas and are highly developed, and economic growth, population growth, and transportation are tied to the urban center. Clearly, basic rural areas experience greater transportation challenges.

The rural transportation system is characterized by disparate parts, substantial decentralization, and different levels of government (city, county, state, federal) funding maintenance of roads, and the operation of rural public transit is primarily the responsibility of local government (Dye Management Group, 2001). The primary focus of this chapter is on the transportation issues and concerns for persons with disabilities in basic RFT communities. Accessibility refers not only to being able to use public transportation but also to transportation as the "connection between the community and its needs, and livability, the characteristics that make the community a desirable place to live" (Shoup & Home, 2010, p. 6). As persons with disabilities in RFT areas are faced with fewer services and available jobs and training locally, transportation becomes critical for successfully accessing many of the services that can assist them in various facets of their lives.

Transportation is considered to be a basic but essential need for ongoing health care (Syed, Gerber, & Sharp, 2013) and additional professional services one might require. Yet, residents with disabilities and service providers in RFT communities often report lack of transportation as one of the most significant and persistent barriers to accessibility (National Council on Disability, 2005a). Moreover, adults with disabilities are twice as likely as those without disabilities to have inadequate transportation (Centers for Disease Control, 2005; National Council on Disability, 2005a, b). Transportation and mobility play key roles toward equal community access for persons with disabilities (PWDs) because affordable, reliable, and accessible transportation allows access to important opportunities that include, but are not limited to, education, employment, health care, housing, and social involvement. For PWDs in RFT areas, the need is especially great (American Association of People with Disabilities [AAPD], 2016). Of the over 2 million PWDs who never leave their homes, lack of transportation is the reported reason for 560,000 (US Department of Transportation, 2003). Transportation has historically been labeled as one of the greatest barriers to PWD (Saunders, Leahy, McGlynn, & Estrada-Hernandez, 2006), and in light of the report from the US Census Bureau (2011) indicating that roughly 8.6 million PWDs live in rural areas, transportation inadequacies may result in even more significant hardships for these residents. Furthermore, the Bureau of Labor Statistics (2013) report the second highest cause for unemployment among PWDs is lack of transportation (11.7%). Considering RFT communities have greater percentages of PWDs, ensuring available and accessible transportation is critical.

Barriers to Rural Transportation

Transportation barriers have a significant impact on PWD's opportunities to fully participate in their community (see Table 3.1). Adequate, accessible transportation is necessary to facilitate social and vocational involvement (Christensen, 2014; Crudden, Sansing, & Butler, 2005; Iezzoni, Killeen, & O'Day, 2006; National Council on Disability, 2005a, b). In RFT communities, residents often experience greater traveling distance for everyday needs (i.e., grocery shopping, paying bills, doctor visits, socialization, etc.). Therefore, families with access to transportation are much better positioned to engage in activities that facilitate well-being. People with disabilities travel less frequently and are more likely to rely on public transportation than the general population (Penfold, CLeghorn, Creegan, Neil, & Webster, 2008). Often, geographic distance, extreme weather (see Chap. 33), and challenging roads (i.e., unsafe and underdeveloped roads) limit residents from accessing services. Even if individuals are able to overcome these challenges, choice of transportation other than a personal automobile is often limited or nonexistent (Pucher & Renne, 2005). Transportation barriers in RFT communities include (1) households distributed over large geographic areas, (2) low population density resulting in decreased demand, and (3) unpredictable level of demand (Valega, Nelson, Wright, & Farrington, 2014). The lack of transportation has been identified as a critical problem for individuals living in rural communities (Arnold & Seekins, 1998; Research and Training Center on Disability in Rural Communities [RTC], 1995; Rojewski, 1992), and, as the result of unavailable, inaccessible, and unresponsive transportation, individuals' ability to access necessary services is significantly affected (Rojewski, 1992; RTC Rural, 1995).

Table 3.1 Barriers to rural transportation

Barrier	Example
Availability	No public options exist
Accessibility	Older buses without lifts and infrastructure barriers
Lack of appropriate infrastructure	Curb cuts, sidewalks, paved roads, street lights, covered and accessible bus stops
Limited bus schedules	Operates from 6:00 am to 9:00 pm (results in challenges for those working atypical shifts)
Long commute distances and travel times	Frequently more than 30 miles
Limited number of bus stops	PWDs may have difficulty getting to the nearest stop
Lack of information for bus schedules, fares, and routes	Limited access to main bus terminal to acquire necessary information

Although transportation may be available, if it is not available to *everyone*, then it is not accessible (RTC Rural, 2012). Accessible transportation includes all aspects of transportation (e.g., public transit systems, vehicles, routes, stops, infrastructure), which should meet or exceed the minimum requirements set forth in the Americans with Disabilities Act (National Council on Disability, 2015).

Considering accessibility, thorough assessment of the barriers precluding PWDs from full utilization of transit options is warranted. Assessment variables include traveling distance to a bus stop and whether the route has a clear and accessible path (e.g., sidewalk, even pavement, curb cuts), clearly demarcated bus stops, and accessible seating. In urban areas, bus stops are commonplace, but in rural communities, even if a bus is available, the stop may be a significant distance from one's home. Moreover, if a bus stop exists, it is frequently uncovered and lacks accessible seating. Rittner and Kirk (1995) reported that public transit services were not only inconsistent, but bus stops were of poor quality and perceived to be unsafe. Operational challenges exist for available bus services, including significantly limited bus schedules, and although schedules may accommodate shopping and appointment needs, they are not suited, due to the variation of hours worked, to transporting individuals to places of employment (RTC Rural, 2012).

Infrastructure

Infrastructure is operationalized as physical barriers to effective transportation in rural communities – the environmental features required to support accessible transportation for PWDs. A developed infrastructure is critical to economic opportunity, quality of life, and inclusion (Council of Economic Advisors, n.d.). As one considers the landscape of a typical urban or suburban environment, a number of commonalities can be found: accessible sidewalks, crosswalks with signals (frequently with both visual and auditory alerts), curb cuts, bus stops with appropriate signage, paved roads, and numerous sheltered bus stops. Accordingly, safe and accessible rights-of-way are critical elements of community life and are essential to viable transportation for PWDs (AAPD, 2016). Although most rights-of-way are built and maintained by local governments and often comply with ADA standards, communities are not mandated to provide infrastructural changes if they do not already exist (Rosenbloom, 2007). These environmental factors, although not commonly considered, allow PWDs to be mobile and have access to the various transportation modalities.

RFT communities, on the other hand, exhibit considerable variation with regard to the existence and quality of such features and, as the result of declining population, have been presented with new challenges in the preservation and management of infrastructure. In rural communities, it is not uncommon to have paved roads with open ditches on the sides, which results in pedestrians having to walk along the side of the road, which is often comprised of loose material (Easter Seals Project Action, 2011). The absence of sidewalks makes accessing a bus stop and boarding the bus challenging. Individuals who use wheelchairs require curb ramps to cross streets to reach a bus stop, yet certain types of curb ramps (e.g., diagonal) are unsafe for a person with a visual impairment (Thatcher et al., 2013). Therefore, even if rural communities currently have public transportation options, getting to the bus stop may be exceedingly difficult or impossible (Iezzoni, Killeen, & O'Day, 2006). For a community to plan to address the barriers for PWDs previously discussed, securing the necessary resources can present difficulties.

Transportation Funding

Compared to the federal resources allocated to urban areas, the allocation for rural transportation is inequitable (NCD, 2015). As of 2010, over 25% of the US population resides in rural communities, yet only 6% of federal transit funding is allocated to serve them (Association of Programs for Rural Independent Living, 2010). Rural areas often fall through the cracks of federal transportation policy, which focuses on statewide priorities for building new highways and often lacks consideration for local needs and preferences. Federal funding is allocated to most rural areas through state departments of transportation (DOTs), while small metropolitan planning agencies (MPOs) and rural planning organizations (RPOs) have limited decision-making authority and control over funding. The decisions that affect local transportation initiatives are often made with little attention to local needs and concerns of the community (Transportation for America, n.d.).

This lack of available funding, both at the state and federal level, can prevent local government agencies and transportation providers from meeting the needs of all consumers. Moreover, according to the Dye Management Group (2001), funding for such projects in many rural areas can prove daunting as the result of insufficient funding provided by the state and a limited financial base from which to levy taxes to generate project income. Unfortunately, the transportation infrastructure is principally maintained by local property taxes, and federal assistance for local rural infrastructure is largely nonexistent (Hossain, Romanoschi, & Emig, 2003).

As a result of increased automobile use, public transportation, which relies heavily on passenger fares, has become increasingly reliant on public subsidies and limited funds from the federal government (American Association of Retired Persons, 2012). Although the funding dilemma persists, there are a number of options available to rural communities, which will be discussed in detail in the following pages.

Geographic Challenges

Although sufficient funding undoubtedly resolves some of the transportation barriers, many rural areas continue to face challenges that are specific to topography and geography. Urban communities differ significantly from their rural counterparts in many ways, and the environmental landscape is one of the main obstacles to address. Although there are accessible routes leading to and from most rural communities, the distance one is required to travel to necessary destinations (e.g., health care, employment, shopping) presents challenges. The low population densities of rural communities, and the resultant distances and travel times between needed services, make it significantly more difficult for rural residents to reach necessary targets (Pucher & Renne, 2005). This concept has been demonstrated in a number of studies addressing barriers for individuals receiving health care (Guidry, Aday, & Zhang, 1997; McCray, 2000; Okoro, Strine, Young, & Balluz, 2005). The long distances between rural residences, employment opportunities, and necessary services create significant unmet need for transportation options in rural communities. Additional features found in rural areas include steep grades, mountain passes, and often poorly maintained roads, which makes providing public transportation in rural areas especially complex and expensive (Kihl, Knox, & Sanchez, 1997). Furthermore, extreme weather conditions may result in difficulties keeping roadways and rights-of-way clear for vehicle and pedestrian use. For a more detailed description of climate and geographic challenges in rural communities, see Chap. 33.

Federal Transportation Policy and Programs for Persons with Disabilities

Equity in transportation for persons with disabilities is mandated in various bills and legislation. Yet, with reauthorization of those mandates, funding amounts and policy needs continue to be hotly debated. On one hand, the debate is focused on political ideology and resources. On the other hand, the debate is fueled by arguments on inclusion, empowerment, and social justice. Because persons with disabilities are disproportionately reliant on public transportation, any change in resources available to support public transportation disproportionately affects them (Gaylord, Abeson, Bosk, Timmons, & Lazarus, 2005). In this section we discuss relevant legislation and programs that address transportation for persons with disabilities.

The Rehabilitation Act of 1973 Although the Rehabilitation Act of 1973 is considered by many to be the seminal legislative means through which transportation for PWDs was brought to the forefront of public discourse, federal assistance for transportation for PWDs began in 1944 with the Social Security Act (Poister, 1982). Effective legislation, however, wasn't established until 1970 when the Urban Mass Transportation Assistance (UMTA) Act of 1964 was amended with section 16, which established a national policy for the elderly and PWDs to "have equal status with other persons in being able to utilize mass transit facilities and services" (Poister, 1982, p. 7). Ultimately, legislative policy regarding transportation services for PWDs was solidified with the passage of the Rehabilitation Act of 1973. Section 504 of the Rehabilitation Act of 1973, commonly known as the civil rights bill for PWDs (Dempsey, 1990–1991), provides that:

> No otherwise qualified person with handicaps in the United States…shall, solely by reason of her or his handicap, be excluded from participating in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. (Rehabilitation Act of 1973a)

Therefore, programs receiving federal funds (e.g., rural communities and transit systems) may not discriminate against those with disabilities based on their disability status, which translates to ensuring available and accessible transportation options.

The 1973 act as amended provides discrimination protection to persons with disabilities and includes issues relating to discrimination (e.g., transportation). One of the challenges with the various legislative pieces lies in assessing and demanding compliance, similarly found with the implementation of the Americans with Disabilities Act toward employment. Besides ensuring PWDs are not discriminated against regarding those entities receiving federal funding, Section 508 of the Rehabilitation Act of 1973 stipulates that all electronic and information technology must be made accessible to PWDs. This would include transit schedules necessary for transportation planning.

> Individuals with disabilities who are members of the public seeking information or services from a federal department or agency to have access to and use of information and data that is comparable to the access to and use of information and data by such members of the public who are not individuals with disabilities. (Rehabilitation Act of 1973b)

Unfortunately, the exact service requirements for transit system operators were not identified. Although there have been numerous legislative mandates since the passage of Section 504 of the Rehabilitation Act of 1973, this act serves as the foundational legislative act for accessible and equitable transportation for PWDs.

The Americans with Disabilities Act The Americans with Disabilities Act (ADA), passed in July 1990, was designed to eliminate discrimination against persons with disabilities in areas such as employment, public services, telecommunications, and transportation. The ADA is recognized as the landmark civil rights law that addresses the rights of persons with disabilities. Moreover, Subtitle B of Title II further solidifies transportation requirements set forth in Section 504 of the Rehabilitation Act of 1973 (Rubin & Roessler, 2008). Title II also extends the requirements beyond those transportation systems receiving federal funding to include public transportation systems not receiving funding (U. S. Department of Justice, 1992). The ADA significantly expanded transportation options for PWDs by mandating public bus and rail operators to provide accommodations, such as lifts and ramps, to afford those who use wheelchairs equal access to services.

Title II of the ADA (http://www.ada.gov/pubs/adastatute08.htm) addresses accessibility and accommodation in public transportation (e.g., city buses and public rail) and prohibits discrimination by entities providing public transportation (Kaun, 1995). Under the ADA, discrimination on the basis of disability in public transportation is prohibited; all new vehicles used in public transit must be accessible; key existing rail stations and all new rail stations and facilities must be accessible; and transit operators must provide paratransit (on-demand, door-to-door) services for those who cannot use available mass transit (AAPD, 2016). The ADA spelled out what was necessary to make all transit options accessible to PWDs. In particular, Title II emphasized the minimum requirements for infrastructure design at transit stops (e.g., landing pads, shelter requirements, accessible paths, signage). Furthermore, as described by Koppa et al. (1998), paratransit is no longer considered a substitute for accessible fixed-route service – rather, both are required. The specific requirements of the ADA discuss that transit operators shall provide complementary paratransit services that are similar to the fixed-route system (Sec. 37.121). Qualified users of the paratransit would include those PWDs who are limited in their ability to travel from a point of origin to the nearest fixed-route stop or are unable to board the bus at the stop. Additionally, Title II includes that public agencies can only buy accessible vehicles for fixed-route services (Sec. 37.71) and for demand-responsive services (Sec. 37.77). For a more detailed discussion of the ADA and its impact on PWDs in rural communities, see Chap. 31.

Surface Transportation Legislation In 1991, a landmark piece of legislation, the Intermodal Surface Transportation Efficiency Act (ISTEA), was passed, which resulted in increased funding (particularly to nonmetropolitan areas), increased local decision-making, and collaboration with the private sector. ISTEA was the seminal piece of legislation giving rise to a number of effective legislative bills. In 1998 and 2005, the Transportation Equity Act for the twenty-first century (TEA-21) and the Safe, Accountable, Flexible, Efficient Transportation Equity Act: A legacy for Users (SAFETEA-LU) were passed, respectively. TEA-21 gave states and localities increased flexibility in allocating funding: a portion of which was designated for rural communities (Stommes & Brown, 2002). Similarly, SAFETEA-LU authorized $286.5 billion to fund the nation's transportation network, including paratransit and grant programs related to transportation for persons with disabilities (AAPD, n.d.). This bill originally expired in 2009, but several short-term extensions extended provisions through 2012. In July of 2012, the Moving Ahead for Progress in the twenty-first century (MAP-21), a $105 billion surface transportation authorization, reauthorized the SAFETEA-LU and was signed into law. MAP-21 includes apportionment for Statewide and Nonmetropolitan Transportation Planning, which includes provisions to increase accessibility and mobility of people, improve quality of life, and increase the safety of the transportation system (North Central Texas Council of Governments, 2016a).

Signed into law in 2015, the Fixing America's Surface Transportation (FAST) Act (23 U.S.C. 135) is the most current legislation that directly applies to surface transportation and will continue through 2020. The FAST Act authorizes $305 billion over fiscal years 2016 through 2020 for highway, highway and motor vehicle safety, public transportation, motor carrier safety, hazardous materials safety, rail, and research, technology, and statistics programs. Additionally, the Statewide and Nonmetropolitan Transportation Planning mandates from MAP-21 were reauthorized and amended to direct planners to focus on intercity buses, bus facilities, and vanpool providers (North Central Texas Council of Governments, 2016b). Section 3006 addresses the enhancement and mobility of seniors and PWDs by improving coordination of services, Section 3007 provides formula grants for rural areas, and Section 3023 reemphasizes paratransit. Although the intent of these laws is admirable, little progress has been made with regard to transportation barriers in rural communities.

The federal government currently funds and administers several programs that provide resources to help improve transportation options for persons with disabilities. These programs include the 5310 Program (Elderly and Persons with Disabilities), the 5311 Program (Nonurbanized Area Formula Grants), 5316 Program (Job Access and Reverse Commute Program [JARC]), and 5317 Program (New Freedom Initiative Transportation Program).

The 5310 Program The 5310 Program (49 U.S.C. 5310) provides formula funding to nonprofit agencies to help increase transportation options that connect the elderly and PWDs directly with needed services by removing barriers and expanding options (Federal Transit Administration, 2016a). Funds are apportioned based on each state's share of the population for those two groups. This program is particularly important because it assists the elderly and PWDs in meeting transportation needs where services are unavailable, insufficient, or inappropriate (NCD, 2015). Nonprofit agencies do not receive funding directly; instead, states apply on behalf of non-private agencies. Funds are restricted for use only for capital projects (projects that help maintain or improve infrastructure) and almost all funding is used to purchase vehicles. States (20%) are required to match federal funds (80%). States' departments of transportation then make decisions about how funds are distributed to nonprofits (Gaylord et al., 2005).

The 5311 Program The 5311 Program (49 U.S.C. 5311 (b)(3)) are formula grants for rural areas that provide funds for capital, planning, and operating assistance to states to support rural transportation in areas with populations of less than 50,000 (Gaylord et al., 2005). Similar to the 5010 Program, an 80/20% match is required; however, a higher match for the local portion is required when funds are used for operating assistance. Additionally, each state is required to spend at least 15% of its allocated amount for the development of intercity bus transportation (Federal Transit Administration, 2016b). The 5311 Program offers significant apportionment to assist rural communities in establishing or the improvement of existing public transit services.

The 5316 Program The Job Access and Reverse Commute (JARC) Program (49 U.S.C. 5316), established in 1998 as an amendment to TEA-21, is designed to address the unique transportation challenges of welfare recipients and other low-income individuals seeking employment (Federal Transit Administration, 2016c), who are largely located in suburban areas. The program was designed to aid both urban and rural areas, but the legislation highlighted the unique transportation needs of rural communities and how employment is negatively impacted (Stommes & Brown, 2005). The JARC program consists of two components: (1) access to employment through the establishment of improved transportation (e.g., shuttles, new bus routes) and (2) reverse commute by providing transportation to suburban employment from distant locales. Due to the fact that few jobs are located in low population density rural areas where public transportation is unlikely, residents have little choice but to travel long distances to work, which makes JARC highly necessary (Kaplan, 2005).

State and local governments, nonprofit organizations, and local transportation providers are eligible for these funds. Although this program is not designed to serve rural areas, 20% of funds are only made available for these communities with a population less than 50,000. Moreover, this program is also not specifically aimed at PWDs but is considered a resource connecting the large numbers of PWDs living in rural communities to employment. Recipients are required to provide a 50% match for operating and a 20% match for capital projects, and funds are distributed through a competitive grant process but historically have been earmarked for specific projects (Gaylord et al., 2005).

The 5317 Program New Freedom Initiative Transportation Program (49 U.S.C. 5317) was created by the 2005 SAFETEA-LU legislation and is designed to go beyond the ADA in finding new ways to provide transportation for PWDs (Seekins, Enders, Silvia, & Rural Institute, 2010). The New Freedom Program is a formula grant, which is apportioned to local transportation providers, and 20% must be allocated to rural areas. The funds may be used for providing rides, training, or capital purchases. The New Freedom Program affords rural communities the opportunity to fund transportation initiatives for PWDs.

The Easter Seals Project ACTION (Accessible Community Transportation in Our Nation) Project ACTION was initiated by Congress to foster collaboration between the disability and transit communities to promote accessible transportation. Easter Seals administers the project through a cooperative agreement with the US Department of Transportation, Federal Transit Administration. The project provides training, technical assistance, and a full catalog of resources to the disability and transportation communities (Gaylord et al., 2005). The overriding goal of Project ACTION is to promote equal access to transportation for PWDs.

Models of Rural Transportation for People with Disabilities

Approximately 41% of the rural population lives in counties with no public transportation (Rural Disability and Rehabilitation Research Progress Report, 2007). Public transportation systems serve the general public without restriction and are typically organized in one of three models: fixed-route services, demand-response services, or deviated fixed-route services (Seekins, 2007). Fixed-route service, typically a bus, consists of the service traveling on a consistent path on a regular schedule. For riders who cannot use the fixed-route service, demand-response may be a feasible option. With this service, riders can call in advance to arrange a time to be picked up and taken to his/her desired location. Deviated fixed-route services operate as a hybrid between fixed-route and demand-response services where the vehicle operates on a fixed-route, but drivers can deviate based on prescheduled requests.

Although the lack of available and accessible transportation presents PWDs with significant challenges, various alternative programs and approaches such as ridesharing, transportation vouchers, accessible taxis, volunteer drivers from nonprofit organizations or local government agencies, and paratransit have been implemented to help rural resident with disabilities obtain transportation to work, school/training, and health care services. If transportation options are to be effective for those living in rural areas, the one-size-fits-all mentality must be abandoned and replaced with a creative and individualized approach (NCD, 2015).

As a result of funding challenges and increased consumer demand, rural communities are faced with finding alternative modes of transportation for PWDs. Voucher programs are one such alternative that have proven to be feasible options for providing transportation services which are nonexistent or inaccessible. Vouchers are tickets that eligible riders who are transportation disadvantaged can exchange for rides (Haarstad, 2008). Vouchers provide an effective solution for individuals who do not have access to transportation options and enable funding agencies (e.g., state offices of vocational rehabilitation, Chamber of Commerce, United Way) to pay public and private transit providers where services exist or to access community resources (e.g., volunteer drivers) where transit is unavailable. The voucher system affords individual increased independence and choice, which results in improved mobility for all users (NCD, 2015). Among the available options for the voucher program, service providers are volunteers and taxi services, which can be invaluable in filling the gaps in existing transportation services while allowing volunteers to receive reimbursement for trips and taxicabs to increase revenue. Also, volunteers and taxicabs can offer increased flexibility for riders when existing options (e.g., paratransit) are not convenient or available.

A rapidly developing business model that may prove beneficial to persons with disabilities with limited transportation options living in rural areas is transportation network companies (TNCs). TNCs serve as intermediaries between those seeking to pay for rides and potential drivers. Transportation experts have described this model as peer-to-peer ridesourcing (Rayle, Dai, Chan, Servero, & Shaheen, 2016). The TNC provides an online or mobile app to connect rider and driver and a fee upon the completion of the transaction (Geron, 2013). Drivers are private contractors working individualized schedules, with many drivers working for multiple TNCs (Rayle et al., 2016). Due to the prohibitive cost of implementing public transportation in rural areas, TNCs create flexible opportunities for services to be offered with minimal investment.

Although potential alternative transportation options exist for individuals living in rural areas, a reasonable solution has yet to be implemented. For those areas where public buses are available, the ADA stipulates that public transit systems provide complementary paratransit services for individuals who are unable to board even an accessible bus or do not have an accessible path to an accessible bus (Rosenbloom, 2007). Paratransit service is a mode of flexible passenger transportation that does not follow fixed routes or schedules and can offer door-to-door service. According to the ADA guidelines, paratransit must operate within a three-quarter mile radius of existing fixed routes and offer service commensurate with fixed-route hours of operation. Eligibility for paratransit service is based on functional considerations to determine which people can most benefit from availability. The vehicles often feature modified vans with lifts to accommodate passengers who use wheelchairs. Paratransit passengers must complete an application and be certified as eligible to use the service (see Table 3.2). Typically, riders can expect to pay up to double the cost of fixed-route fare for an ADA complementary trip, and trip times can be negotiated with the service provider. Additional challenges relate to denial of eligibility, untimely pickups, minimum 24-h lead time on reservations, and extended wait times (National Council on Disability, 2015). Although paratransit offers a valuable service to complement fixed-route bus service, for those living in a rural community without public bus service, paratransit is not considered a viable option.

Table 3.2 Paratransit eligibility requirements

Documentation	Examples
Category 1 – people who can't travel on an accessible bus due to a disability	1. People with cognitive disabilities who may not know when to get off of the bus to reach their final destination 2. People with visual impairments who may not be able to navigate to their destinations
Category 2 – individuals who require accessible buses	One who uses a wheelchair and is able to use an accessible bus but needs to travel to a destination not served by accessible options
Category 3 – people who have a specific disability-related condition that prevents them from getting to the boarding location	1. One who uses a wheelchair but cannot access the bus stop due to geographical or infrastructure barriers (e.g., steep grades, unpaved roads, no sidewalks) 2. A person who walks with a cane and must walk one mile to the nearest bus stop
Supporting documentation	1. Letter from disability service provider (e.g., VR counselor, independent living coordinator) 2. Letter from medical provider 3. Detailed listing of specific barriers (e.g., lack of sidewalks or curb cuts, terrain)
In-person interview with transit personnel	Functional assessment

Note: Adapted from Disability Rights Education and Defense Fund (DREDF)

Summary

Transportation is the critical medium affording PWDs access employment, education, health care, and independent living. Many communities in the USA provide their citizens with a range of transportation options, but the same cannot be said for most rural communities. In fact, the lack of transportation options has been cited as one of the most significant challenges faced by PWDs living in rural communities (Gonzales, Stombaugh, Seekins, & Kaznitz, 2006). Rural residents make up a significant percentage of the US population, but only a paucity of funding is allocated to serve their transportation needs. Although personal vehicles remain the primary means of transportation for individuals living in rural communities, PWDs may be unable to drive and not have access to a personal vehicle nor have supports to transport them to necessary destinations, which makes public transit crucial.

There have been a number of legislative mandates in the past few decades to address transportation barriers for PWDs, but, unfortunately, little impact has been realized in rural areas. Challenges persist for rural communities regarding finding effective and creative solutions to overcome the financial barriers affecting transportation. Improving infrastructure and increasing accessible and available transportation options take funding, but once the necessary advancements have been made, more residents will likely be able to access employment, thereby increasing local tax revenues resulting in a prudent investment. For communities to make progress, these efforts must be viewed as a long-term investment rather than a short-term expenditure.

Although several reasonable options have been presented in this chapter, many rural areas would likely benefit from collaborating with other communities who have made progress in addressing transportation barriers. Options certainly exist, but solutions take the concerted effort of all affected parties working together toward a common goal. No quick fixes are available to overcome inadequate rural transportation, and we certainly have not presented every potential option, but we hope to have offered potential strategies and generated discourse, which will ultimately lead to improvements.

Rural transportation offers a fertile area of research to determine realistic, fundable options to provide transportation for those most in need. Solutions to issues affecting the well-being of a disadvantaged group seldom occur quickly; a continuous, concerted, and persistent effort can result in the necessary solutions resulting in a more equitable transportation system for all commuters.

Discussion Box

Why are we talking about transportation in rural areas?

In the chapter, we learned that although available and accessible transportation is not something many of us consider in our daily lives, for those living in rural communities, it is critically important. There are a number of reasons for the lack of transportation in rural areas (e.g., funding, improper infrastructure, geographical and topographical difficulties), and, as a result, the daily lives of those residents are drastically affected. When we then consider the impact on individuals with disabilities, the significance of inadequate transportation options becomes more salient. Research is clear that the most common form of transportation in rural communities is the private vehicle, but frequently individuals with disabilities are unable to drive themselves. For those with disabilities, having access to transportation is necessary to get to and from medical appointments, employment, and shopping and to afford them the opportunities to fully participate in life. The ADA was passed to ensure that individuals with disabilities had equal access to all of the opportunities and services available to those without disabilities, and its affects have been tremendous. Unfortunately, even the most well-intentioned law will have loopholes, and rural transportation is one example. A paucity of research exists on transportation barriers in rural communities, but, as a result, opportunities for studying the intricacies abound. Rural living offers many benefits, but available transportation options are not one of them. If communities are willing to devote time and money to improving transportation options for residents, more people may consider relocating to rural areas positively affecting the tax base. Ultimately, transportation needs to be available to all individuals with disabilities regardless of where they live. Quality of life, participation, and general well-being are contingent upon it.

Case Study

Jim is a 42-year-old male who had a car accident 4 years ago resulting in a traumatic brain injury (TBI) and leaving him without the use of his legs. He uses a manual wheelchair and is quite proficient at getting around. He recently moved from the city to a rural community in the northeast because he inherited the home of his recently deceased mother. He doesn't own a car but has become accustomed to riding the bus to work and other locations around town. Prior to moving, he learned that there was a bus stop about 100 yards from his new home. He knew he could easily wheel himself that far, so he had no concerns about his transportation needs.

The day after he moved in he was preparing to head to the bus stop to go to work. He left his home and quickly realized that there were no sidewalks on his narrow road. He tried wheeling on the shoulder, but the gravel made it quite challenging. Although he eventually made it to the bus stop, once there, he saw that there were no curb cuts to allow him to get up to the landing pad. He was able to climb the curb in his wheelchair to wait for the bus. Upon the buses arrival, he waited for the life to be lowered, but he was told that it was nonfunctional. Two patrons exited to help Jim get into the bus. While lifting his chair, Jim's weight shifted and he hit his head on the railing of the bus, which resulted in a gash in his head.

1. Considering that Jim lives in the northeast, what are some additional barriers he is likely to encounter?
2. Although helping Jim board the bus was a kind act, what are the ramifications of this decision?
3. Does Jim have any other transportation options? Why or why not?

Resources

Consortium for Citizens with Disabilities Task Force: www.c-c-d.org/rubriques.php?rub=taskforce.php&id_task=15

Community Transportation Association: www.ctaa.org

Disability Gov's Guide to Transportation: www.disability.gov/resource/disability-govs-guide-transportation/

Federal Transit Administration: www.fta.dot.gov

National Rural Transit Assistance Program: www.nationalrtap.org

Project Action: www.projectaction.org

United We Ride: www.fta.dot.gov/CCAM/www/index.html

The American Public Transportation Association (APTA): www.apta.com

Transportation for America: www.t4america.org

U.S. Department of Transportation: www.dot.gov/accessibility

Learning Exercises

1. List and describe the three types of rural communities?
2. Discuss the differences between availability and accessibility.
3. Describe five (5) barriers to accessible transportation related to infrastructure.
4. Discuss some of the major challenges to the availability of rural transportation in rural communities.
5. Discuss the positive and negative issues relating to paratransit.

Field-Based Experiential Assignments

Multiple Choice Questions

1. What percentage of federal funding is allocated to rural communities?
   (a) 10%
   (b) 6%
   (c) 2%
   (d) 15%
2. Compared to those without disabilities, adults with disabilities are ______ times more likely to have inadequate transportation.
   (a) Five
   (b) Ten
   (c) Two
   (d) Eight
3. In the USA, what percentage of rural residents has no public transportation options?
   (a) 40%
   (b) 32%
   (c) 28%
   (d) 50%
4. Which of the following is **NOT** considered a benefit of public transportation?
   (a) Lower household expenses due to the freeing up of income for other uses
   (b) Allows communities to keep taxes low for all residents
   (c) Improved economic efficiency by providing access to employment
   (d) Improved mobility of residents
5. What was the first piece of legislation mandating federal assistance for transportation for people with disabilities?
   (a) Urban Mass Transportation Assistance Act
   (b) Social Security Act
   (c) Rehabilitation Act
   (d) Americans with Disabilities Act
6. Which title of the ADA mandates that private transportation systems must comply with accessibility requirements?
   (a) Title I
   (b) Title II
   (c) Title III
   (d) Title IV
7. Which piece of legislation resulted in increased funding of transportation in non-metropolitan areas, increased local decision-making, and improved collaboration with the private sector?
   (a) SAFETEA-LU
   (b) MAP-21
   (c) FAST
   (d) ISTEA
8. Which of the following programs is a formula grant for rural areas to provide capital,

planning, and operating assistance to support rural transportation with a population less than 50,000?
   (a) 5310
   (b) 5311
   (c) 5316
   (d) 5317

9. Which program was designed to address the unique transportation needs of rural communities relating to employment?
   (a) MAP-21
   (b) JARC
   (c) New Freedom Initiative Transportation Program
   (d) ACTION
10. A typical bus is an example of which one of the following models of transportation?
   (a) Fixed-route
   (b) Demand-responsive
   (c) Point-of-Service
   (d) Deviated Fixed-route

Key

1 – B
2 – C
3 – A
4 – B
5 – B
6 – B
7 – D
8 – B
9 – B
10 – A

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4

The Role of Technology in Service Delivery for People with Disabilities in Rural Communities

Stacie L. Robertson

Overview
This chapter focuses on the role of technology in service provision to persons with disabilities in rural areas, examining both the reasons for including technology and the challenges in using technology in service provision. The issues involved are viewed from both the counselor and the consumer perspective. The chapter begins with an introduction, discussing the Digital Age, assistive technology in service provision, and the legislation that supports the use of technology and persons with disabilities.

The chapter continues by discussing the accessibility of technology, services to rural areas, and how technology can enhance services in these communities. This section addresses the barriers faced in rural areas including barriers in training counselors and access to the needed infrastructure for individuals living in rural areas. Infrastructure issues reviewed included the needed access to the Internet, fiber optics, and the necessary equipment (computer, Internet, smartphone, video capabilities, etc.). Additionally, personal factors that affect the use of technology are discussed.

Following the discussion regarding technology use and accessibility, the chapter reviews the therapeutic relationship as it is affected by the use of technology. This section of the chapter is followed by a discussion on the legal and ethical issues and concerns regarding the use of technology in service provision. The last two sections of the chapter offer recommendations and suggestions for the barriers addressed and future implications regarding the use of technology in service provision.

Learning Objectives
This chapter will provide answers to the following questions:

1. What are the ethical and legal concerns with using technology to provide services to individuals with disabilities in rural areas?
2. What are the barriers to accessing technology in rural areas, specific to persons with disabilities?
3. What are the steps agencies must take to enhance the use of technology in reaching out to individuals with disabilities in rural areas?
4. How can a standard of care be established for use of telecommunications in service provision?

Introduction

The Digital Age officially began in the 1970s with the advent of the personal computer. In the nearly 50 years since this time, technology has

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S.L. Robertson (✉)
Department of Special Education, Rehabilitation and Counseling, California State University, San Bernardino, San Bernardino, CA, USA
e-mail: Stacie.Robertson@csusb.edu

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advanced at an accelerated pace. In the 1970s desktop computers were expensive and bulky, and the Internet, when first introduced, was slow and clunky. Today, a large portion of the population carries a faster, smaller, lighter version of a computer in their pockets. Smartphones and the advances in how we access the Internet have drastically changed our world. With the right equipment, you can have real-time conversations with individuals who are sitting right next to you just as clearly as you can speak with someone across the globe.

Over these last 50 years, we've moved from an Industrial Age to the Information Age (also known as the Computer Age or the Digital Age). As far back as 1980s, Masson, Collins, and Cox (1986) noted that compared to other occupations, the majority of individuals in Western societies are hired to collect, handle, and distribute information. In the 1990s the rise of automation in the workplace saw a movement toward replacing humans in jobs where an automated machine could function. Machines can now be programmed to do many things including driving and parking cars, running assembly lines, and even conducting some surgical procedures. These are characteristics of the Information Age, a forward movement to creating smarter, faster technology that is meant to enhance productivity in regard to employment and occupations. These changes in technology can also assist service providers in enhancing the lives of individuals with disabilities, making time and distance less and less of a problem in service delivery.

In service delivery, researchers have been examining ways to reach rural populations through the use of technology for several years (Ross, 2016). The term "telecommunications" refers to communicating through an electronic means and can include phones, email, and the Internet through cables, wires, and over fiber-optic lines. Terms like "telehealth," "telecounseling," and "telepsychology" refer to the practice of providing health services, counseling, and vocational rehabilitation over a distance and often times to individuals living in rural areas using various means of telecommunications. The extent to what is considered telecommunications is varied and can include simply talking with a consumer over the telephone or through text message. More complicated means of telecommunication may include email, video conferencing, through Internet websites, online support groups, or even through applications developed for the use with smartphones. On a global scale, we have used telecommunications to assist in service provision through national text messaging crisis lines and a new method of using a smartphone application, which allows for private messaging, to be used with individuals in domestic violence situations (Bell, 2016).

Discussion Box 4.1

Crisis hotlines have become a cost-effective way to de-escalate an individual in the moment of a crisis and a way to direct them to various mental health resources. The purpose of these hotlines is to decrease feelings of hopelessness and reduce the likelihood of suicide in callers. The service is also used to ensure that individuals receive immediate assistance and referrals for resources as needed (Evans, Davidson, & Sicafuse, 2013). The National Suicide Prevention Lifeline reports that the 165 member centers, in the year 2014, answered about 1.5 million calls (Draper, 2015). While we know the general use statistic, the statistic that is more difficult to estimate is the ages of the callers. It is suspected that less than 5% of these calls are made by individuals 18 years old and younger (Evans et al., 2013). With text messaging being used so extensively by individuals between 12 and 17 years old, the development of a text message crisis line allows service providers to reach adolescents in a way that matches the way in which they communicate. When asked, adolescents indicated that they find text messaging to be more comfortable, private, and readily available compared to face-to-face communication. Additionally, researchers believe that, with this population in particular, text messaging allows the individual to spend the time discussing the actual issue or concern more directly. While there are limitations to text messaging crisis interventions, such as the limitation of not having nonverbal cues and voice inflection cues, this means of reaching adolescents especially is gaining popularity. Text messaging crisis lines may aid in increasing help-seeking behaviors and provide an avenue to reach a crisis counselor at any time day or night. For individuals in rural areas, these hotline service providers may be one of the only options for crisis services. Individuals with disabilities, already making use of text messaging, may also find this form of communication less stigmatizing and more private as well.

Throughout the literature, psychologists (Gray, Hassija, Jaconis, et al., 2015), social workers (Mattison, 2012; Reamer, 2013), vocational counselors (Ispen, Rigles, Arnold, & Seekins, 2012a; Johnson, 2004), occupational therapist, and educators (Casey, 2008) have documented the benefits of providing services and education through telecommunications to individuals in rural areas. These researchers often cite ease of access and cost reduction as the main motivators to employing telecommunication methods as a means of reaching individuals (Ipsen et al., 2012a).

Researcher and legislation have examined the use of assistive technology and individuals with disabilities. Specific to vocational rehabilitation, the Institute of Rehabilitation Issues (IRI, 2002a, 2002b) has examined how technology can be used to enhance vocational services to individuals with disabilities. Conducting assessments; contacting consumers through email, text, or real-time video conferencing; teaching job search skills; applying for positions; and researching job openings, all serve as a few of the many uses telecommunications in providing services for individuals with disabilities. More recently the Institute of Rehabilitation Issues (IRI, 2010) provided recommendations that include developing policies to support the use of technology to assist both employees of VR agencies and to assist the participants of services. The IRI suggested counselors use technology to provide services to consumer but also emphasized greater efforts be made to use technology as a means of accommodating disability when appropriate. These recommendations are supported by legislation such as the Assistive Technology Act of 2004 (P.L. 108–364), the Individuals with Disabilities Education Act (P.L. 94–142), and the Americans with Disabilities Act (P.L. 110–325). Additionally, the recent Workforce Innovation and Opportunity Act of 2014 (P.L. 113–128) encourages digital literacy or the training of individuals to use technology to reach their educational and vocational goals. These governmental legislations provide support for the use of and access to assistive technology provided to children and adults with disabilities.

Accessibility of Technology

Individuals with disabilities consistently have lower employment rates than individuals without disabilities. Individuals with disabilities also continue to be at a disadvantage in regard to income, transportation, and other key areas that may affect life satisfaction (Barzegarian & Sax, 2011). Of concern for individuals with disabilities, in rural areas, is that while employment rates rise in metro areas, the rates of unemployment in nonmetro or rural areas are not rising at the same pace. Additionally, poverty rates in nonmetro areas are consistently higher than for individuals living in more metro areas (USDA ERS, 2016). Social services have become one of our primary means of assisting in alleviating poverty and unemployment.

Barriers to receiving these social services in rural areas are created by several factors, including financial limitations and transportation issues that affect both the consumer and the agency providing services. The offices in which services are provided may be at a great distance from the consumer, and public transportation may not be an option. Service providers calculating the cost must consider the overall expense of traveling itself (gas, automotive maintenance, per diem if appropriate, etc.) and the time that traveling may take away from one's ability to see additional clients. Rural areas often have agencies that serve several counties, with consumers living hours away from the office. The time, alone to travel to the various different counties to meet with the consumers, face-to-face, is a natural limiter to the quantity of services that can be provided. Therefore, both monetary expenses and the service provider's caseload size may prohibit them from frequent home visits. The use of telecommunications then becomes a necessary way to provide cost-effective services. While telecommunications may be cost-effective, providing services via technology still comes with barriers and complications.

To examine various barriers in the use of technology in providing services, Ispen et al. (2012a, 2012b) conducted exploratory studies to determine access to, use of, and attitudes toward using telecommunication in providing vocational rehabilitation services in rural communities. In the first study, Ispen et al. (2012a) surveyed over 1000 vocational rehabilitation counselors regarding their use of telecommunications. The survey looked at available methods of telecommunication, agency support in using telecommunications, counselor attitudes and experiences in using telecommunications, and barriers presented to and by the consumers using the services. Ispen et al. found that the majority of the counselors surveyed (98%) had access to the Internet and email, and most believed that telecommunications enhanced their ability to provide VR services (73%). Few counselors in the study, however, reported agency support, training on the use of telecommunications, or technical support needed to use the telecommunications.

While the counselors reported using telecommunication methods, such as email and the telephone, to reach out to both urban and rural consumers, overall the counselors in these communities reported having fewer communications with rural consumers regardless of the nature of communication (face-to-face or telecommunications). Based on the study, counselors reported that their rural consumers did not have the same access to computers with Internet access and did not have email addresses. Other issues included a concern with the consumer's ability to communicate in writing through email, either based on literacy issues, comprehension, language barriers, and/or disability factors such as visual impaired/blind, hearing impaired/deaf, cognitive disabilities, and mental illness. The disability factors such as low vision/blindness may also imply limited access to accommodations allowing consumers to fully utilize telecommunications (i.e., a screen reader that allows for text to speech for individuals who are visually impaired). In this study, counselors reported that approximately 50% of their rural consumers did not have access to a computer with the Internet or know how to use the Internet to enhance their vocational rehabilitation.

In the second Ispen et al. (2012b) study, recruiting consumers from seven different agencies, for a total of 225 respondents, the researchers found that nearly all of the consumers had access to a cell phone, land line telephone, or both (96%) and that many (78%) had cell phone service. Although at a bit higher than estimated by the counselors in the first study, this second study found that a little over one-half of the participants had access to a computer with Internet access and an existing email address. In contrast to what the counselors expected in the other study, however, nearly 70% of the participations said that they could access a computer with Internet in their community, and over 60% indicated that communicating with their counselor over email was acceptable. On the other hand, however, similar to the findings of the first study, certain consumers with certain disabilities, such as those with cognitive impairments, were less likely to use the telephone or email telecommunications. In a study looking specifically at a disability that often hampers communication, Johnson (2004) linked telecommunications and VR services, providing video conferencing to individuals who are deaf or hearing impaired.

The participants in the Johnson (2004) study found video conferencing to be better than using the phone or those who preferred to communicate using American Sign Language.

The studies mentioned, being mostly exploratory, provide us with an opportunity to examine the thoughts of both counselors and consumers of services and how telecommunication can be used to enhance service provision. The main barrier highlighted in the exploratory studies by Ispen et al. (2012a, 2012b) was disability or disabling conditions as they factored into the methods of telecommunications used by the VR counselors. Telephones and email were not accessible to all consumers whose disability affects their ability to interface through voice or written communications. In these studies VR counselors and consumers noted that email, text, and telephone were the most readily available forms of telecommunication. Access to telecommunications, therefore, is multilayered when thinking about how telecommunications can assist individuals in rural areas with obtaining services. The first concern is the access that is provided by the agency for the counselor or human service provider. Counselor technology literacy, agency support, and training in telecommunications along with access to other forms of telecommunication such as video conferencing could bridge some gaps. On the other hand, there is the consumer and his or her knowledge, access, training, and support in the use of telecommunications in general but also in his or her access to assistive technology that will make the smartphone, email, or computer accessible, considering his or her disability (i.e., screen reader, enlarged text, predictive keyboards, video options).

Consumer access to the appropriate telecommunication devices and applications for their particular disability comes with additional concerns for consumers in rural areas. Along with disability factors, barriers may include demographic and personal factors. The Ispen et al. (2012b) study examined age and college education along with disability as variables that might factor into the use of telecommunications and the belief that it is acceptable to use for rural disability-related services. While age was not a significant factor in the reported study, there is a concern regarding the use of technology and the consumer born prior to the technology boom who did not use computers and technology during their education. Ownership, use, digital literacy, and technology literacy may be an issue for those consumers who have not been previously provided with education and training in telecommunication devices and applications.

Technology research indicates that the owners of items such as a smartphone (i.e., cell phone with Internet access) are more likely younger people under the age of 50. The Pew Research Center reported in 2015 that smartphone ownership starts at over 80% ownership for individuals 18–49 and drastically dips to a little over 50% for those 50–64 years old and as low as 30% for those over 65 years old (Anderson, 2015). This limits access to text messages and smartphone applications that may assist the process such as *FaceTime*, which could be used for video conferencing. Computer ownership does not see as much fluctuation based on age with 70–80% of individuals 18–64 years old owning a computer (desktop or laptop) and 55% of individuals 65 and older owning a computer (Anderson, 2015). Computer ownership does not, however, indicate knowledge of use, access to the Internet, or an ability to troubleshoot any technology issues that may arise in the use of the computer for services.

Along with age and disability, Ispen et al. (2012b) examined education level of consumers to determine if education was connected to the use of technology and a belief that technology use was appropriate in service provision. They found that individuals with some college education reported significantly higher rates of communicating with their counselors through telecommunications and indicated a significantly higher acceptability rating then those consumers with a high school or less education. This is also supported by the Pew Research Center (Anderson, 2015) information that reports that over 90% of individuals with some college education owned a smartphone and 90% owned a computer.

Other factors addressed by the Pew Research Center included race/ethnicity, household income, and community type (urban, suburban, and rural). Overall, smartphone ownership is affected by age, household income, education, and community type with individuals from rural areas with less household income less likely to own a smartphone. Computer ownership, however, is affected by race/ethnicity, age, household income, and education with little difference in ownership across community type (Anderson, 2015). According to Pew Research Center, broadband access (the ability to use the Internet) at home is affected by race/ethnicity, community type, household income, and education levels. Rural residents and African Americans were a little over 50% likely to have broadband at home and individuals with lower incomes and less education under 50% likely to have access to the Internet from their homes (Horrigan & Duggan, 2015). The FCC reports that in the year 2016, 20% of rural America lacks access to broadband services at speeds fast enough to use email, while 39% of rural America lacks the speeds to conduct video conferencing, online education program, or even a general online internet job search (Federal Communications Commissions, 2016). This fits with the counselors in Ispen et al. (2012a) reporting that only about 50% of their caseload had access to the Internet at home. Access to the Internet, ownership of telecommunication equipment, a knowledge of how to use the equipment, and the assistive technology needed to adapt the telecommunication equipment to fit with the disability may be needed for many of the individuals that could benefit the most from telecounseling and distance service provision.

Therapeutic Relationship

Telecommunication, especially email and text correspondence, introduces the possibility of misunderstanding. Counselors worry that the telecommunication methods used to reach rural clients may interfere with the counseling relationship (Simpson & Reid, 2014). In the counseling literature, Bordin (1979) discusses the term “therapeutic alliance.” This term or concept describes the bond between the client and the counselor. In his research Bordin indicates that the therapeutic alliance includes the factors of goal agreement, trust development, and the collaborative quality of the counseling/counselor relationship. In other words, how well do the counselor and client work together toward obtaining a predetermined and positive outcome? This ability of the counselor and client to work together on shared goals, tasks, and expected outcomes is a reliable predictor of both positive outcomes and client attrition (Donnell, Lustig, & Struser, 2004; Simpson & Reid, 2014). Considering the importance of the therapeutic alliance to the client outcomes, it is critical to examine the effects of using technology on the counseling relationship. Issues such as miscommunication, poor writing skills, language comprehension, reading comprehension, and lack of access to nonverbal cues may pose a threat to the alliance.

Legal and Ethical Issues

Historically legal and ethical issues have been the biggest hurdles in using technology to provide counseling and services to individuals with disabilities. Laws on use have not been able to keep pace with the advancements in technology. For example, a law may be in place governing the provision of counseling to individuals in other state via Internet counseling; however, the recent use of text messaging as a crisis intervention may not yet be addressed. In the mid-1980s Mason, Collins, and Cox (1986) outlined what they called “the four ethical issues of the information age.” Technology has changed drastically since the article was written, yet, the four ethical issues remain a problem to be addressed when using technology in the workplace. The four issues presented are *privacy*, *accuracy*, *property*, and *accessibility*. How do we keep the information private? Is the information we have accurate? Who owns the information and how accessible is the means in which we are trying to provide services? The questions posed by Mason, Collins, and Cox were originally presented for individuals in business, but similar questions have emerged regarding technology in the human service fields. Researchers in rehabilitation counseling (Reimer-Reiss, 2000), social work (Reamer, 2013), and psychology (APA, 2013) continue to look at issues of *privacy* (or confidentiality), *accuracy*, *property*, and *accessibility.* In addition, and specific to human services, are issues of *informed consent*, *competence*, and *risk management* (Reamer, 2013).

To address some of the concerns, the American Psychological Association (2013) has adopted suggestions on ethical guidelines to address issues as related to telecommunications in counseling. They provided eight guidelines that address concerns of assuring that the technology-based services meet a standard level of care similar to what one would expect when receiving in-person services. Special attention was paid to ensure that consumers or clients are informed of the additional risk of online or technology-assisted services, and the counselor is doing everything possible to minimize risk and potential breaches of confidentiality.

Although service providers may be well versed in the general aspects of ethical codes assuring that the standards are met in providing services, the addition of technology requires more specific knowledge. While the ethical codes mandate that counselors not practice outside of their scope of knowledge, for those using technology for service provision, adherence to the code needs to be extended to include competency in the use of technology. If video conferencing is the best way in which to provide services to a rural client, the service provider's knowledge of service profession can only be demonstrated if he or she also has knowledge of the programs needed to conduct the video conferencing. Similarly, accessibility in the case of teleservices includes not only access to services through the agency but also access to the necessary technology and/or infrastructure to obtain the information and access to the information or the ability to interact with the information (i.e., ability to search for information online or ability to interact with members of an online support group).

In addition to ethical concerns, APA (2013) guidelines indicate a need to be knowledgeable of the laws and regulations and how they may differ across states and/or between jurisdictions. Providing services to consumers who are out of state at the time of service provision and/or agencies that serve neighboring counties in connecting states will need to be assured of the differences in laws and regulations regarding services. Currently, licensure for many health-related services (i.e., licensed professional counselors, psychologist, licensed social workers) is regulated and governed by the individual state. Individuals licensed in one state are not automatically licensed in another state. Using southern Illinois as an example, within an 80-mile radius, four states (IL, KY, IN, and MO) have varied rules, regulations, and requirements for licensure and possibly different regulations regarding using telecommunications in service provision. Service providers in rural areas will need to be especially aware of jurisdiction changes on the state and county level.

Overall, researchers and agencies can clearly identify the benefits in providing services to individuals in rural areas through the use of technology. It is cost-effective, efficient, and a great way to reach consumers who may not otherwise be served. The psychology literature also indicates that consumers may be more open to talking online with the added benefit of a certain level of anonymity, and consumers with strong written communication skills often benefit from writing out their concerns (Ross, 2016). Currently, however, in the rehabilitation literature, the barriers of service provider competency, consumer competency, disability factors, location, income, and age may factor into the limited use of telecommunications in service provision.

Recommendations and Suggestions

The Institute on Rehabilitation Issues (IRI, 2002a, 2002b) has developed suggestions on the use of telecommunications in the vocational rehabilitation process. Similarly, the American Psychological Association (2013) has developed and adopted guidelines used to direct the use of telecommunications in providing psychological services. The two documents provide a foundation for the development of recommendations and suggestions for including technology in the delivery of services for individuals with disabilities in rural areas. These documents address the key areas needed to assure that services can be provided through technology. These key areas include the agency, the service provider, the standards for services, and the consumer.

Agencies

Ispen et al. (2012a) reported that a large percentage of counselors in their study (98% of 1187 counselors) had agency-supported access to computers and wireless Internet. The majority of the agencies supported the use of email and phone communications. The number dropped drastically, however, for supported text messaging capabilities (6%) and video conferencing (14%). Similarly, only 20% of the counselors believed that their agency completely supported using telecommunications in service delivery, and only 29% believed they had access to technical support when needed. The number of counselors who had received any training in the use of telecommunications in service delivery was also low (29%). Examining the connection between training and the use of technology, the researchers were not surprised to find that the counselors who were trained in using technology in delivering services were more likely to use technology in delivering services. Thus, supporting the argument that supports the use of technology in service provision begins with agency support and needs to include training and technical support.

The results of the Ispen et al. study illustrate how agency support or lack of agency support affects the use of technology in providing services. The first step in developing strategies for delivering services with the use of technology therefore includes gaining agency buy-in to the process. Providing training opportunities, releasing time to obtain training, and providing technical support are steps in developing agency support. Additionally, providing access to the use of different types of technology or telecommunication devices can enhance and better enable the use of technology in service provision. Ispen et al. noted that many counselors have access to very little more than email and telephone services to contact consumers. The concern, however, is that either due to disabilities or due to literacy issues, only 50% of consumers are able to access telephones or make use of email.

Providing training and support to the service provider is one way in which the agency can express support for the use of technology in providing services. Additionally, agencies overall presence on the Internet can bolster the use of services in general. Developing an agency website and/or making use of social media and interactive Internet platforms can provide an inexpensive way to reach consumers. An agency website that holds information on agency services, programs, as well as vendor and referral programs can provide an additional means of bringing in consumers and also provide them with the information needed to conduct an informed choice. Social media platforms such as *Facebook* and *YouTube* provide agencies with an opportunity to provide up-to-date information and to make their content interactive for the consumer. Institute on Rehabilitation Issues (2002a) suggestions include using the website as a means of assessing consumer satisfaction and providing round-the-clock access to agency information and as a means of marketing the agency and/or program.

Service Providers

Agency buy-in is the first step in providing teleservices to individuals in rural communities. The second step or second hurdle is counselor or service provider buy-in and training. As mentioned previously in the chapter, counselor competencies in this area include both knowledge and skills of service provision but also knowledge and skills in using various types of technology. Technology literacy, digital literacy, and information literacy all refer to the knowledge, skills, and ability to effectively use technology and/or access information through the Internet. While a video conference call may be the best way to provide services to a rural consumer who is deaf, a counselor with little understanding of how to conduct a video conference call is unable to provide services in this manner. The IRI (2002a) suggestions for digital or information literacy include the following:

> (a) having an understanding of different media and technologies, (b) using the ability to think critically, (c) having an understanding of ethics, (d) evaluating information properly, and (e) communicating to put the information to work for people with disabilities. (p. 33)

Many service providers of today tend to be in the age group that did not grow up with computers and may not have computer skills. Basic computer knowledge, training, and support in learning different methods are essential in developing a standard for providing services via technology. Gaining general computer and technology competencies is needed in addition to learning and making use of those technologies that are specific to individuals with various disabilities. Often individuals who are deaf communicate better via text or instant message or through video conferencing where sign language can be used. In preliminary studies on the use of technology, neither text messaging nor video conferencing was used often by the counselors (Ispen et al., 2012a), which added to the issues of access. Knowledge of how screen readers, for those with visual impairments, handle information emailed or uploaded to a website and a working knowledge of what is being termed “text speak” may also help the service provider in meeting the needs of the consumer. Overall, having an understanding of the various assistive technologies that can alter information input (i.e., dictation programs) and those that alter information output (text to speech) is needed by the service provider to assure access for the consumer.

Standards for Services

In the midst of the Digital Age, those agencies and service providers not making use of technology are creating a disservice to themselves and to their consumers. An overall standard of care, however, has to be maintained regardless of how services are delivered. Those individuals receiving services through telecommunication should not feel as if they are receiving a substandard of care that is used only when the main methods are not available. This standard of basic care should include the careful consideration of potential ethical and/or legal concerns with providing services online, through the telephone or over the Internet.

One of the main concerns is assuring that consumers have privacy and that information is kept as confidential as possible. The first step the agency may wish to review their policies and procedures regarding the use of technology. Are agency policies so lax that private information is available to non-agency personnel or so strict that service providers are allowed to use portable technology (i.e., laptops, phones, or tablets) to access consumer information outside of the office? To find a balance, policies should be reviewed to find ways to enhance services to individuals in rural areas. To give surety that information shared over the Internet is kept confidential, agencies and service providers may need to obtain the necessary infrastructure and security software that provide the encryption of data, emails, and any client files. Included in the concern of privacy is the need to assure that data is disposed of in an appropriate manner. Recognizing that simply deleting a file may not clean it from storage and determining that web searches, data, and other information is routinely cleared from computer web browsers (APA, 2013) become a priority.

An additional standard of care suggestion is that agencies and service providers serve as advocates for technology use among and for their consumers. As mentioned previously, often, rural areas lack the infrastructure needed to support Internet services in rural communities. Consumers may not have access to the broadband needed to obtain Internet in their area and may have limited cell phone services. Furthermore, consumers who have low income may also have limited access to technology and limited access to the Internet. In the Digital Age, information is being shared via the Internet. Lack of access is as important as a lack of transportation and a lack of accessibility in the workplace. Advocating at the local, state, and national level for increased access to the Internet assists the consumer in receiving services and also increases their chances of changing their level of income or status. With the necessary access and training, consumers who can receive services via online methods are more likely to also be able to obtain employment that can be done at home via online methods as well.

Consumer

Agency support, service provider training, and the development of policies and procedures to develop a standard of care all fall flat if the consumer is unable to access the technology or make use of telehealth services. As indicated in the research studies (Ispen et al., 2012a, 2012b), about 50% of consumers were unable to access email or telephone communications. Some issues were disability related and an inability to access the information in the format used and some issues were language and/or reading comprehension concerns, while other concerns were general access and limited use of or knowledge of different technologies that could be used.

Individuals who do not have access to technology (computers and/or Internet access) at home could possibly obtain access at the local library or community center. To this end Ispen et al. (2012b) reported that 70% of the consumers polled for their study indicated that computers and Internet services were available to them within their community. Community access to computers and Internet services, however, presents issues with physical accessibility of the facility, access to any modifications needed for their disability and concerns of confidentiality. Will a discussion on a public computer in a public setting remain private? Will the consumer remember to log out after the discussion and will he or she remember to clear computer of any personal information prior to logging out of the computer? Often public facilities also put time limits on the use of their computers, and library or community center hours may not match up with the hours that services can be provided. To resolve some of these issues, it may also behoove agencies to work together to provide access to technology. For example, a VR agency located in County A, that serves Counties A–E, may develop a relationship with an Independent Living Center in County E, to allow consumers to use their computers and Internet services to receive distance telerehabilitation from the VR counselor who is residing in County A.

Similar to the issues of competency with the service provider, overall computer, technology, and digital literacy is needed with the consumer as well. Does the consumer know how to effectively and efficiently use the technology necessary to obtain services in this manner? Technology can be used to obtain services, set meetings with the service provider, conduct searches for medical information, join online support groups, apply to college, take online courses, and even apply for jobs. The need to fully understand how to access this information on one's own is a big part of assuring that the rural client is provided equitable services. The service provider then would need to provide support, training, and possibly even coaching to assure that the consumer takes on the task of learning how to best use technology (IRI, 2002a). Training, educating, and coaching can also be a shared task either across agencies or through the use of natural supports that the consumer may have more readily available. Perhaps

Research Box 4.1

See Cihak et al. (2015).

As discussed in the chapter, using technology to provide services to individuals with disabilities in rural areas comes with several challenges. One such challenge is the individual's digital literacy. Legislative

Acts addressing disability and employment, most recently, have all touched on the need to assure that individuals with disabilities have digital literacy skills. Digital literacy and the devices used to communicate online (smartphones, tablets, computers) facilitate better vocational opportunities, greater productivity at work, and greater independence at work, home, school, and life and provide a means of social inclusion. Using a single-subject research design called a multiple-probe design, Cihak et al. developed a study to teach four individuals with intellectual disabilities how to use email, across multiple platforms (laptop, tablet, and desktop computer).

Method: The four student participants in the study had some knowledge of the basics of computers but had not been able to independently use their email accounts prior to the intervention. Prior to teaching the skills, the researchers conducted a task analysis laying out the individual steps needed to access an email account, respond to an email, and compose a new email to a peer tutor. From turning on the device to signing out after sending the email, the researchers identified 21 steps in the task analysis. The procedures for the study included a baseline phase, a digital literacy instruction phase, and a maintenance phase. The digital literacy targeted emailing from a desktop, computer, then a laptop, and finally an iPad tablet. Instructions included providing verbal directions and demonstrations and practicing opportunities with reminder cues on how to complete the task, along with verbal and physical prompts to show students how to complete each step of the task. Finally, the maintenance phase tested the student's skills 9 weeks following the training.

Results: The students increased their mean percentage of task-analyzed steps following the training. Students were able to email independently, completely on average 86% of the tasks, after a mean of seven sessions, for the desktop with similar results for the laptop and iPad tablet. All students were able to understand the instructions 9 weeks later and were able to email as requested at this follow-up time. The study gives further details on each student's skill acquisition and maintenance skills following the training. Overall their average scores went from a mean in the 20% range to a mean score in the 90% range following the training.

Discussion: Each individual was able to acquire the skills and show maintenance of the acquired skills 9 weeks following the training. The skills were additionally maintained across the various platforms. Training across the various platforms served as a means of providing generalized learning in an effort to provide a basis for learning newer, updated platforms in the future. In the Digital Age, training must be inclusive of the fact that technology will continue to change. This study provides a means of developing training schedules for teaching individuals how to use the technology needed to enhance services to individuals with disabilities in rural areas.

enlisting the help of a family member who can provide instruction and guidance to the consumer or working with the local libraries and community centers to assist them in aiding the consumer could add to the consumer's digital literacy.

To assure that consumers in rural areas with disabilities are allowed as much access as possible, service plans and/or treatment plans will need to include necessary telecommunications and telecommunication training. Assisting a consumer in financing a computer, assuring that an individual has voice recognition software, and/or training someone to use video conferencing may enhance services but also may enhance the consumer's personal, educational, and employment opportunities as well. Service plans of the future will need to include technology as well as the assistive technology needed to access the digital information that is available to others. Many of the consumer barriers to technology access can be addressed in assuring that assistive technology is in place along with the original device. Assuring that service providers are using technologies that best fit the consumer's disability, communication and language concerns may be as simple as using video conference instead of an email or an email instead of a phone call. Service providers in conjunction with the consumer will need to search for and learn how to use those technologies that best fit with the consumer's abilities as opposed to using those technologies that are the most readily available (i.e., email and telephone).

Discussion Box 4.2

Legislation such as the Assistive Technology Act of 2004 (P.L. 108–364), the Americans with Disabilities Act (P.L. 110–325), and the Workforce Innovation and Opportunity Act (P.L. 113–12B) encourages service providers to work assistive technology into service plans for persons with disabilities and encourages the provision of education on digital literacy. To provide services to individuals in rural areas through telecommunication, individuals will need the devices necessary to access the services. Assistive technology is categorized as either "hard" or "soft" technology. Hard technology includes physical items that do not need human interactions to function (e.g., computers). Soft technology on the other hand is those things that require human interactions (e.g., decision-making and training). Assistive technology encompasses a board range of devices from low tech (e.g., pencil grips, splints, paper stabilizers) to high tech (e.g., computers, voice synthesizers, computer screen readers, braille readers). The goal of technology in working with people with disabilities is to enhance the employability, education, communication, and daily functioning activities. In assuring that an individual can access the Internet, email, call, or video conference with service providers, it is important to assess the individual's assistive technology needs. Based on functional limitations can a person type, read, hear, or see what is being communicated. Some things to keep in mind when selecting assistive technology include the following:

The person's functional needs and/or limitations.
The cost to purchase, train, maintain, and/or repair the device or technology.
Durability of the device and operability and dependability of the device.
Proper training and follow-up services to master the use of the device.
Potential of device increases the individual's level of independence.
The level of independence needed.
The amount of independence will the device give the individual.
Ease of use and safety to use independently.

Future Implications and Summary

The beginning of the Information Age looked drastically different than the world we live in today. While computers were large, clunky, and only accessed by the wealthy, currently smartphones, laptop computers, and tablets have brought technology to the masses. Most of us could not have predicted the changes made in the last 10–15 years, much less those changes over the course of the last 30 years. Technology is advancing rapidly and has gotten increasingly faster, smarter, smaller, and more and more affordable. With that all we can predict in the next 10–15 years is that technology will change in a way that is expected to be brighter and better than it is now. Applications such as voice recognition, text to talk, and hands-free use of items from phones to car may have been invented for convenience, but these conveniences also serve as almost a universal design, providing individuals with disabilities greater and greater access to technology and digital information.

Greater access to technology as a whole comes with greater opportunities to identify uses for technology in the provision of services. As mentioned within the chapter, smartphone applications are currently helping with domestic violence and crisis counseling. Websites, smartphone applications, and various social media outlets are also currently providing information on diagnosis, treatment, and first aid for many medical conditions. Individuals can locate online counseling, support groups, and other individuals with similar disabilities. While we used to bring a person into an agency for peer counseling or mentorship, individuals can now search out a mentor online who may live next door or may reside across the world.

As technology changes with the speed of light service providers, ethical boards and legislators will need to strive to keep up with the trends. Although governing bodies such as the American Psychological Association (APA, 2013) have developed guidelines for standards of care, they are also quick to point out that what they have produced is a guideline and not a requirement, standard, or regulation. Standards have been and continue to be adjusted as technology advances. In particular, who can service what consumers and where the services can take place are issues that many researchers continue to discuss (Ross, 2016). Governing bodies seem to be contemplating issues of licensure and jurisdiction with regard to distance, Internet, and telecounseling services. Questions such as whether licensure in one state allows for serving a client using distance or telecounseling methods in another state are important to clarify. More broadly, can state licensure boards work out a form of reciprocity that takes into account the needs of a more technologically advanced world? These are questions to be addressed as we advance in our efforts to provide services via technology.

Our research on the use of technology in providing services to individuals with disabilities is still in the exploratory phase. Even though Ispen et al. (2012a, 2012b) have done an excellent job of exploring the thoughts and actions of vocational rehabilitation counselors and consumers, studies are still needed to determine a connection between distance service provision and consumer outcomes. From the literature it appears that we have reviewed the barriers and have determined where we need to make changes to assure that we can offer services at a distance for rural consumers. Once offering services through the use of technology is utilized and explored more completely in a more standardized manner, our next step is to assure that these methods meet the needs of the consumers. Can we provide services at a distance for rural individuals with disabilities that lead to positive, social, medical, and vocational outcomes? This question remains to be answered.

Resources

1. The American Counseling Association, American Psychological Association and the Commission on Rehabilitation Counselor Certification have each addressed the use of technology and distance counseling in their ethical codes for professionals.

   American Counseling Association Ethics Code – Adopted 2014.

   Section H: Distance Counseling, Technology, and Social Media. https://www.counseling.org/resources/aca-code-of-ethics.pdf

   American Psychological Association Guidelines for Practice of Telepsychology. http://www.apa.org/practice/guidelines/telepsychology.aspx

   Commission on Rehabilitation Counseling Certification Code of Ethics – Adopted 2017.

   Section J: Technology, Social Media, and Distance Counseling. https://www.crccertification.com/filebin/pdf/Final_CRCC_Code_Eff_20170101.pdf
2. Funded through the Federal Assistive Technology Act, each state has an Assistive Technology Act Program that provides Assistive Technology support and assistance. Some programs provide training, device lend-

ing libraries and information and referrals regarding Assistive Technology. You can find your state ATAP on the following website: https://www.ataporg.org/programs

3. Centers for Independent Living (CIL) provide various services to individuals with disabilities and are available in every state. Often these centers provide services to individuals in rural areas with some having satellite offices in the most rural areas. CILs can be partnered to provide technology training, accessible technology or space for service provision. The Independent Living Research Utilization (ILRU) program provides a directory of CILs, alphabetized by state, then divided by county:http://www.ilru.org/projects/cil-net/cil-center-and-association-directory
4. Purple's Video Remote Interpreting (VRI) is an "on-demand service" that provides a sign language interpreter via webcam for communications between individuals who are deaf and individuals who are hearing and in need of a sign language interpreter. Purple: https://signlanguage.com/vri/
5. The Job Accommodations Network (JAN) is a source of information on disabilities, disabling conditions, accommodations and employment. JAN works with both employers and employees, consulting on issues of accommodations, related legislation and disabilities. JAN: https://askjan.org/links/about.htm
6. The Institute on Rehabilitation Issues (IRI) offers materials that address issues of importance in public rehabilitation or working with individuals with disabilities. Various publications specifically address technology, distance education and the Internet as a resource for service providers. IRI Publications: http://www.iriforum.org/books.aspx

Key References

1. Anderson, M. (2015). The demographics of device ownership. The Pew Research Center: Internet, Science and Tech. Retrieved from http://www.pewinternet.org/2015/10/29/the-demographics-of-device-ownership/

   Pew Research Center conducts research, public opinion polling, demographic research and media content analysis along with other empirical social science research. Pew Research is a subsidiary of The Pew Charitable Trusts. Pew Research Center, Internet, Science and Tech provides data on technology, use and access: http://www.pewinternet.org/
2. Americans with Disabilities Act of 1990, Pub. L. 110–325. Retrieved from https://www.gpo.gov/fdsys/pkg/PLAW-110publ325/pdf/PLAW-110publ325.pdf
3. Assistive Technology Act of 2004, Pub. L. 108–364. Retrieved from https://www.gpo.gov/fdsys/pkg/PLAW-108publ364/html/PLAW-108publ364.htm

Case Study: Jacquelyn Thomson

Jacquelyn is a 42-year-old white female. She is a single parent of two young boys who are 6 and 8 years old. Jacquelyn and her sons live in a small rural town in Southern Illinois. The small town has a population of 800 people. The town closest to her is a 45-minute drive away and has a population of 20,000 people. This town is the biggest town within a 100-mile radius from her house. There are several small towns within a 50-mile radius, with her local human services office (i.e., public aid, vocational rehabilitation, one-stop shop) being in a town that requires she drive over an hour.

Jacquelyn is a trained Certified Nursing Assistant (CNA) and has worked in the local nursing homes since her divorce 10 years prior. At work one evening, in transferring a patient, Jacquelyn hurt her back. She had to drive 100 miles to find a doctor that could diagnosis her as having spondylolisthesis, a condition in which one of her vertebrae has slide forward over the bone below. Her condition affects her L5/S1 vertebra with the slip being listed as

Unstable and a Grade 1. She is not a candidate for fusion surgery, but the slip has caused a pinched nerve. She is in a fair amount of pain and has been warned that continuing to lift heavy objects will cause her vertebra to further slip which puts her at a risk for paralysis, bowel and bladder problems, and other long-term issues. Jacquelyn is otherwise a healthy woman who had enjoyed a fairly active life. Her ex-husband has moved out of the area and has little contact with her or their children. Her mother lives on the same street but is elderly and has been getting both physical and financial assistance from Jacquelyn over the last year or two.

As mentioned Jacquelyn's nearest human services offices require she drive an hour from her house. She is unaware of what services are available to her and has been encouraged by the diagnosing doctor to obtain physical therapy (PT), to obtain mobility aids to limit the pressure on her spine, and to consider either obtaining different employment or severely modifying her current job duties. Jacquelyn has been off work since the injury and is obtaining a limited amount of worker's compensation. She is struggling financially and has noted that her pain restricts her ability to sit for long periods of time, including the time it takes to drive to PT, to human services offices, and even to her doctor's appointments.

Questions:

1. What types of services might Jacquelyn benefit from obtaining?
2. What are some ways in which a human service worker could accommodate the fact that Jacquelyn is unable to travel to the offices for services?
    (a) What types of ethical and legal issues must be addressed in providing services in the manner in which you suggest?
    (b) What rural area issues might restrict her ability to obtain services without driving to the offices?
3. Using the Internet resources provided at the end of the chapter, provide a brief description of Jacquelyn's condition and suggested mobility aids, which could increase her mobility or at least decrease her pain.
    (a) What are some personal characteristics that may affect her use of technology and her ability to learn to use such equipment?
4. If you are working to assist Jacquelyn in obtaining new or modified employment, what steps would you take first to assist her in meeting her employment goals?

4. Individuals with Disabilities Education Act of 2004 Pub. L. 108–446 Retrieved from http://idea.ed.gov/download/statute.html
5. Workforce Innovation and Opportunity Act of 2014, P.L. 113–128 Retrieved from https://www.gpo.gov/fdsys/pkg/PLAW-113publ128/pdf/PLAW-113publ128.pdf

Instructional Features

Self-Check Questions

1. What some are reasons for using technology to enhance services to persons with disabilities in rural areas?
2. Other than email and text messaging, what are some ways a service provider can provide services using technology?
3. What are the ethical concerns regarding using technology in the workplace?
4. The chapter addresses various personal issues that might factor into if a person has access to or uses technology. What are a few of these factors?
5. The chapter addresses issues counselors have in using technology in providing services.

What are some ways in which agencies can better support the use of technology in service provision?

Field-Based Experiential Assignments

1. How much information do you have about rural areas and service provision for people with disabilities in rural areas? Using a map, identify a town that is not located within a metropolitan area and has a population between 10,000 and 50,000 people. The town cannot be a suburb of a bigger city or in the county with the bigger city (over 50,000 residents). To fully understand, identify a town that is at least 30–60 miles away from the nearest city of over 50,000 residents. Once you have identified this rural area, use the Internet to locate services in that town or area. Who provides transportation? How would a person get to a doctor's appointment if they could not drive? Where is the nearest hospital and/or doctor's office? Where is the nearest human services office? Do they have mental health services in the area? Do they have medical assistance such as physical therapy, occupational therapy, and speech therapy readily available? Do they have a medical supply store or someone in the town who can repair a broken wheelchair? How far would an individual have to drive to get to a specialist for any physical medical condition?
2. Imagine yourself as having to train someone on the use of technology so that the two of you could later use it to communicate. For this project start with developing a task analysis for training someone how to use your smartphone. Outline the exact steps it takes to unlock, turn on, login, and access your favorite or most used app on your phone. Once you have opened the app, develop the steps it would take to perform the tasks of the app (e.g., play the game, post on the social media site, etc.). End your task analysis with the steps it takes to log off of the app and close out of your phone. Ask a friend to help you try out your task analysis. Using only verbal commands (do not point, touch, or physically assist), direct the individual through the steps. Modify your steps as needed.
3. Conduct a small survey of the people you know regarding their use of email, smartphones, laptops, and computers. Be sure to include individuals from all age groups, people with varied amounts of knowledge and various disabilities (you probably know someone with a disability that is hidden like a learning disability, hearing loss, or low vision). In your survey ask questions regarding their daily use of technology, their knowledge, and the barriers they find in using technology. Finally, be sure to add questions regarding how comfortable they would feel about using technology to interact with a doctor, counselor, or service provider.

Multiple Choice Questions

1. In the Ispen et al. studies, the counselors reported which of the following as a major barrier to their using technology in service provision?
   (a) Lack of computer and/or email access
   (b) Lack of agency support for use of technology
   (c) Lack of knowledge regarding the use of technology
   (d) All of the above
2. In the Ispen et al. studies, the consumers report which of the following as one of the major barriers to their using technology?
   (a) Lack of access to the Internet, computers, or email
   (b) Lack of knowledge on the use of technology
   (c) Limited ability to use technology due to disability
   (d) None of the above
3. According to the chapter, ____________ refers to the knowledge, skills, and ability to effectively use technology or access information through the Internet.
   (a) Digital or information literacy
   (b) Information Age awareness

   (c) Tech-savvy knowledge
   (d) Technological competencies

4. One of the main concerns in standards of care and ethics in providing services via telecommunication is which of the following?
   (a) Access to the Internet
   (b) Knowledge of the use of email
   (c) Privacy and confidentiality issues
   (d) Employment applications issues
5. What are some possibilities for accessing the Internet if a person doesn't have access at home?
   (a) The local library
   (b) A human service agency
   (c) A local community center
   (d) All of the above
6. Bordin's research indicates that ____________includes the factors of goal agreement, trust development, and the collaborative quality of the counseling/counselor relationship.
   (a) Therapeutic alliance
   (b) Counselor/client bond
   (c) Counselor/client goal setting
   (d) Therapeutic togetherness
7. The term used in Question 6 is a predictor of which of the following?
   (a) Negative counseling outcomes
   (b) Positive counseling outcomes
   (c) The likelihood that clients will return for services
   (d) B and C only
8. The Pew Research Center indicates which age group most likely to have access to a smartphone and/or a computer?
   (a) 18–59 years old
   (b) 21–65 years old
   (c) 18–39 years old
   (d) 49–65 years old
9. Mason et al. as far back as the 1980s identified four ethical issues in using technology in the workplace. These issues are:
   (a) Privacy, accuracy, property, and accessibility
   (b) Privacy, accessibility, accommodations, reasonable limits
   (c) Piracy, property accuracy, and accommodations
   (d) Piracy, reasonable limits, privacy, and accessibility
10. Issues specific to technology in the counseling include which of the following?
   (a) Information retrieval, accessibility, and privacy
   (b) Informed consent, ethical mandates, and personalization
   (c) Informed consent, competence, and risk management
   (d) Information retrieval, consent, and risk management

Key

1 – B
2 – C
3 – A
4 – C
5 – D
6 – A
7 – D
8 – A
9 – A
10 – C

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5

Health-Care Initiatives, Strategies, and Challenges for People with Disabilities in Rural, Frontier, and Territory Settings

Erma J. Lawson

Overview

In 2008, the United States faced a financial crisis considered by many economists to have been the worst financial crisis since the Great Depression of the 1930s (American Public Health Association [APHA], 2014; Bagley & Levy, 2014; Bulger, 2010). For example, the monetary upheaval threatened to collapse large financial institutions, in which the national government prevented through bank bailouts. During this period, stock markets dropped worldwide; the housing market suffered, resulting in evictions, foreclosures; and prolonged unemployment (Kaiser Family Foundation, 2014). The economic catastrophe played a significant role in the failure of key businesses; declines in consumer wealth, estimated in trillions of US dollars; and a downturn in economic activity leading to the Great Recession of 2012. Many Americans lost jobs and their health insurance (Blendon, Benson, & Brulé, 2012; Collins, Rasmussen, Doty, & Beutel, 2015).

Simultaneously, health-care costs increased at an unsustainable rate. The US health-care spending equaled approximately $2.1 trillion, doubling the 1996 amount (Blendon et al., 2012). A sense of urgency existed and politicians called for health-care reform and included it in their election and reelection platforms. As a policy goal, the 2008 Democratic presidential election candidates argued for health-care reform. In 2009, President Barack Obama focused on a stimulus bill to repair the deteriorating economy, and in 2009, Democratic leaders introduced detailed health reform proposals to Congress (Kaiser Family Foundation, 2014).

Compared to other industrialized nations, the United States has the most expensive health -care system in the world (Blumenthal, Adams, & Nuzun, 2015; Emanuel et al., 2012). In 2010, per capita health costs in the United States were $8233 as compared with the next highest per capita cost of $5388 in Norway (National Center for Health Statistics [NCHS], 2011). US spending per capita doubled that of most other Western nations, including France, Sweden, Australia, and the UK (NCHS, 2011).

Despite the relatively higher health-care cost, the United States has lower life expectancies and higher infant mortality rates compared to many industrial nations. For example, Canadians live longer than people in the United States. Specifically, women in Canada live an average of 83 years, compared to 80 in the United States; men live more than 78 years compared to 75 in the United States (Woolhandler, Campbell, & Himmelstein, 2003). Importantly, the United States is the only Western industrialized nation that does not provide universal health coverage to

E.J. Lawson (✉)
University of North Texas Department of Sociology, Denton, TX, USA
e-mail: Erma.Lawson@unt.edu

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its citizens (Kaiser Family Foundation, 2014). In 2010, approximately 50 million people in the country were without health insurance (Kaiser Family Foundation, 2014).

President Obama proposed comprehensive, minimally invasive health-care reform to build upon existing frameworks, including Medicare and Medicaid (Orszag & Emanuel 2010; Palmer, 2016). He did not advocate for the creation of a new health system but pursued reform that would increase access to health care and control costs without largely disrupting the current system (Collins, Rasmussen, Garber, & Doty, 2013). President Obama pledged, "If you like your health care plan, you can keep it," which implied that the new legislation would not discontinue existing private health-care plans. Following decades of struggles to reform the health-care system, Congress passed the Patient Protection and Affordable Care Act (ACA) in 2010 with no Republican support (Huntington, Covington, Center, & Manchikanti, 2011).

The Patient Protection and Affordable Care Act, known as the Affordable Care Act (ACA) or Obama Care, is momentous and groundbreaking legislation (Vincent & Reed, 2014). The ACA has been described as the most significant social legislation in the United States since the enactment of Medicare and Medicaid in 1955 (Orszag, & Emanuel, 2010; Sommers, Buchmueller, Decker, Carey, & Kronick, 2013). President Obama signed the final bill March 30, 2010.

The goal of the ACA is to improve the affordability, availability, and quality of health insurance through consumer protections, regulations, taxes, health insurance exchanges, and subsidies to improve health outcomes. Given that rural health-care systems have changed over the past decade and that approximately 54 million Americans – a full 19% of the non-institutionalized population – who suffer from a physical or cognitive disability have major limitations in performing routine activities, the impact of the ACA on people with disabilities in rural communities warrants consideration and special attention (Centers for Disease Control and Prevention [CDC], 2016).

Moreover, people with disabilities in rural communities have high unmet needs. First, their health conditions are often neglected in most of the health promotion and other preventive services (Downey, 2013). In fact, people with disabilities from various age groups encounter health service deprivations. Adolescents with disabilities are often deprived of sexual and reproductive health services; adults with disabilities are often denied routine screening measures or regular health interventions (Finley & Stewart, 2013). Second, secondary conditions such as bedsores and infections, comorbidity, age-related conditions, adoption of high-risk behaviors (e.g., substance abuse, poor lifestyle measures), and higher rates of premature deaths have been reported among people in rural communities. If addressed by stakeholders, such conditions are preventable (Hartley, 2004).

The purpose of this chapter is to discuss the impact of health-care reform on rural residents with disabilities. A special emphasis is place on *service delivery reforms*, which have received little research attention. Most studies have focused on *insurance reforms* (Vincent & Reed, 2014). First, this chapter provides an overview of the Affordable Care Act (ACA), followed by a brief review of rural health disability disparities. Second, the challenges individuals with disabilities in rural communities face are discussed. Finally, the last section presents initiatives and strategies to improve rural health care.

Learning Objectives

Upon completion of this chapter, the reader should be able to:

1. Identify key provisions in the Affordable Care Act.
2. Articulate rural health disparities and the significance of these differences to people with disabilities.
3. Understand the need for health-care reform in the United States.
4. Describe key factors and that might begin to remedy the deficiencies noted in the ACA.
5. Appreciate the impact of the ACA on residents in rural communities.

Introduction

On March 23, 2010, President Barack Obama signed the Affordable Care Act (ACA) into law. For the nearly 60 million uninsured rural Americans, the law addressed the availability of health-care services; increased access to quality, affordable health coverage; a patient-centered emphasis; and stressed disease prevention, cost containment, and patient engagement. Specifically, the Affordable Care Act enables Americans to receive health security by the following comprehensive health insurance reforms: (a) expand coverage, (b) hold insurance companies accountable, (c) lower health-care cost, (d) guarantee more choice, and (e) improve the quality of health care for all Americans. Per the Congressional Budget Office, 12 million people have insurance because they became eligible for Medicaid under the Affordable Care Act. It also provides the *budget and economy a more stable path* by reducing the deficit by more than $100 billion over the next 10 years and more than $1 trillion over the second decade and by limiting government overspending and reining in waste, fraud, and abuse (Blumenthal & Collins, 2014). By ensuring that people have access to preventative measures, the law will save millions of lives as well as taxpayers' money through the elimination of unpaid hospital bills that increase the cost of health care. Most importantly, the Act promotes wellness and public health and provides an unprecedented funding commitment to these areas. It directs the creation of a national prevention and health promotion strategy that incorporates the most effective methods to improve the health status of Americans and reduce the incidence of preventable illness and disability in the United States.

Key provisions of the ACA that address rising health costs include providing more oversight of health insurance premiums and practices; emphasizing prevention, primary care, and effective treatments; reducing health-care fraud and abuse; reducing uncompensated care to prevent a shift onto insurance premium costs; fostering comparison shopping in insurance exchanges to increase competition and price transparency; implementing Medicare payment reforms; and testing new delivery and payment system models in Medicaid and Medicare. Although the law is complex, the key elements can be grouped into two main categories: insurance reform and health system reform (U.S. Department of Health and Human Services [USHHS], 2014). It is important to distinguish facts from myths about the ACA (see Discussion Box 5.1).

Discussion Box 5.1: Key Provisions of the Patient Protection and Affordable Care Act (ACA): A Systematic Review and Presentation of Early Research Findings

French, Homer, Gumus, and Huckling (2016) conducted a systematic literature review of selected major provisions of the Affordable Care Act (ACA). They identified relevant articles from scholarly peer-reviewed journals and reports disseminated by governmental agencies and various organizations. The authors synthesized research findings from the past 5 years regarding the immediate and long-term effects of the ACA. The research shows that the ACA has substantially decreased the number of uninsured individuals. Affordability of health insurance continues to be a concern for most people as health disparities persist by geography, race/ethnicity, and income. Evidence also suggests improvements in access to and affordability of health care.

Discussion Questions:

1. What provisions in the ACA decreased the number of uninsured individuals?
2. What reasons do you think that health insurance, access to health care, and the quality of health care continue to concern rural people with disabilities?
3. What factors in the ACA led to improvements in access to health care?

Note: Adapted from French et al. (2016)

Insurance Reform

The Individual Mandate Beginning in 2014, all Americans are required to buy health insurance coverage or pay a penalty. Designed to increase the number of healthy individuals in the risk pool, policy-makers argued that insurance premiums would increase for the healthy individuals who cannot afford coverage, that is, whose cost of premiums exceed 8% of household income, and those eligible for Medicaid under the Medicaid expansion provision are exempted from the mandate (Kocher, Emanuel, & DeParle, 2010; Sommers, Gunja, Finegold, & Musco, 2015).

The Affordable Care Act limits the scope of insurance companies. In the past, insurance companies denied coverage to adults and children with chronic conditions and placed a lifetime financial cap on paid care or terminated coverage. The Affordable Care Act created a Patient's Bill of Rights that protects consumers from such insurance company practices. Specifically, insurance companies can no longer:

1. Deny coverage or charge more for a preexisting condition.
2. Impose lifetime dollar limits and essential health benefits.
3. Cancel coverage due to an application mistake.

Other insurance reforms included tax credits designed to increase the affordability of insurance, gradual closure of the Medicare Part D prescription drug doughnut hole, and the expansion of the Medicaid programs. The following are specific provisions related to insurance reform.

Medicaid Expansion Medicaid was planned to expand coverage to nearly all low-income Americans under the age of 65. Each state would receive substantial federal support for the expansion. The Medicaid expansion would largely benefit low-income, childless adults who are ineligible for Medicaid coverage in 40 states (Blendon et al., 2012; Kaiser Commission on Medicaid and The Uninsured, 2013). However, the 2012 Supreme Court decision halted the Medicaid expansion by permitting states to opt out of the Medicaid expansion. As of March 14, 2016, 32 states and the District of Columbia declared that they will expand Medicaid. Provisions also include the following: (a) requiring Congress to buy plans through exchanges, (b) taxing tanning salons, (c) denying health insurance to undocumented immigrants, and (d) considering homeless people with disabilities eligible for health care.

Health Exchanges A second type of insurance reform is the creation of health-care exchanges, which are organizations designed to facilitate the purchase of health insurance. Exchanges are marketplaces that provide consumers with standardized health-care plans that provide transparency of benefits and costs. The marketplaces fill a gap for individuals without employer-provided coverage, individuals not old enough for Medicare, and those with financial resources that disqualify them for Medicare (Jost, 2014; Levit et al. 2003; Long et al., 2014).

The ACA provides better access to health care. For instance, insurers are required to cover recommended preventive services, including cancer, diabetes, and blood pressure screenings without additional co-pays or deductible. Additionally, young adults can remain on their parents' plans until age 26. The Health Insurance Marketplace is a one-stop shop where consumers can choose a private health insurance plan that fits their health needs. Most people who shop in the marketplace qualify for financial assistance that lowers their monthly premiums and makes coverage affordable (Keith, Lucia, & Corlette, 2014; USDHHS, 2014).

Health System Reform

Less well known of the ACA reforms are the health system reforms. These provisions are designed to improve quality and efficiency, enhance the health-care workforce, and increase public health and preventive services. Health system reform is an important and significant component of the patient-centered medical home (PCMH) and the Accountable Care Organizations (ACOs). Specifically, the health-care delivery models in the ACA are designed to improve quality and efficiency of health care. Moreover, increased funding for Federally Qualified Health Centers, National Health Service Corps, and school-based health-care centers will increase the quality of public health services (Devers & Berenson, 2009; Fisher & Shortell, 2010).

Patient-Centered Medical Homes Patient-centered medical homes are a team-based approach to health care, with the primary provider serving as a care provider and coordinator. The team includes physicians; advanced practice nurses (called nurse practitioners, NP) or advanced practice registered nurses (APRNs); and other nurses, physicians, physician assistants, pharmacists, dieticians, social workers, educators, and therapists (Auerbach, Staiger, Muench, & Buerhaus, 2013). While this model is not new, and was practiced prior to the ACA in health-care facilities, it provides an impetus for the dissemination of the medical home model (White House Fact Sheet, 2012). Patient-centered medical care homes will provide access to a consistent primary care provider. Thereby, a stable and ongoing relationship with a health-care provider can be established (Collins, Rasmussen, Garber, & Doty, 2015). Per Keeling and Lewenson (2013), five features characterize the PCMH approach:

1. It is patient-centered and emphasizes a partnership among provider, patient, and family where patients are informed and active decision-makers.
2. Care is comprehensive in addressing physical and mental health-care needs, from wellness to acute and chronic illnesses to end of life.
3. Care is coordinated and continuous across the health-care system, from specialty and hospital care to community-based and home health care.
4. Services are accessible in terms of both place and time, through electronic and 24/7 phone communication as well as in-person visits during regular business and expanded hours.
5. There is a commitment to safe care and quality improvement practices.

Information technology, open communication, and culturally competent care are hallmarks of this model. More importantly, the medical team is led by the primary care provider, such as a nurse practitioner or medical doctor (Klein, Laugesen, & Liu, 2013).

Accountable Care Organizations (ACOs) The ACA developed Accountable Care Organizations (ACOs), to be part of the Medicare programs. The goal of these organizations is to reduce health-care costs and to improve quality of care (Devers & Berenson, 2009; Fisher & Shortell, 2010). ACOs provide incentives to primary care health-care providers, specialists, and hospitals to form networks to coordinate care. Medicare assesses penalties if preestablished ACO's goals are not met and provides incentive payments if goals are met (Graham, 2011). Instead of providing rewards for treatment, this provision compensates wellness practices. ACO members are jointly accountable for the quality of care, cost, and overall care of their patients.

Currently, ACOs provide nurses with opportunities to engage in care coordination and patient education, but nurse practitioners are not recognized by ACO's as primary care providers (American Academy of Nurse Practitioners [AANP], 2012; Graham, 2011). The ACA also provides a 10% primary care bonus to clinicians who participate in the Medicare program. Medicaid payment rates to primary care physicians have also increased to match Medicare levels. The ACA authorized $10 million over 3 years for new training opportunities for direct care workers (Cohn, 2010; Hill, 2013; Mechanic, 2012). Grants are available for training of direct workers employed in long-term care settings, nursing homes, and assisted living communities (Devers & Berenson, 2009). Following the training, the trainee must work in the field of geriatrics, disability services, long-term care, or chronic care for a minimum of 2 years (Rickerts & Fraher, 2013; USDHHS, 2014).

Additionally, the ACA authorizes $68 million in grants and incentives to enhance training, recruitment, and retention of direct care staff in long-term care organization or community-based programs or settings (USDHHS, 2014). Grants are also available for demonstration projects lasting up to 3 years to develop ten core competencies for homecare aides and a certification test. The project must include an evaluation (White House Fact Sheet, 2012).

The ACA also includes provisions to promote the quality of long-term care work force that applies to rural communities (USDHHS, 2014). The first part consists of nursing home transparent provisions, which require the federal government to collect and report information on the performance of nursing homes, including staff turnover rates and services residents receive and how much facilities spend on wages and benefits (USDHHS, 2014). The second provision enables states to conduct national background checks, including fingerprint checks, on direct health-care providers. The goal of this provision is to eliminate individuals with criminal records working with vulnerable adults and individuals with disabilities, to ensure the safety of rural nursing home residents (USDHHS, 2014).

To counteract the lack of geriatric education, the ACA requires federally funded geriatric education to family caregivers who support older adults and individuals with disabilities. The two courses are free and are in collaboration with community partners. This provision will assist informal family caregivers in rural communities. Additionally, to strengthen health-care training and support, the ACA requires dementia and abuse prevention training in the certified training for nurse aides (USDHHS, 2014).

The ACA includes provisions to strengthen primary care as well as strategies for minimizing barriers to care including personalized disease management plans to increase utilization rates. These initiatives include symptom education, health education materials, and community-based interventions that improve health prevention and detection behavior. Further, The Affordable Care Act of 2010 also strengthened and expanded the Money Follows the Person (MFP) demonstration grants and program to allow more states to apply (See Kaiser Commission on Medicaid and the Uninsured, 2013).

Finally, mental health is an important component in the ACA. Building on the Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA, 2008), ACA provides benefits for mental health and substance abuse treatment equivalent to other medical and surgical benefits. The ACA requires Medicaid plans offered through state-based insurance exchanges to cover behavioral health services as one of the ten required components of the essential benefit package (Ogundipe et al., 2015). Provisions also encompass preventive psychiatric services, including alcohol abuse screening, counseling for adults, depression screening for adults and adolescents, domestic and interpersonal violence screening and counseling for all women, tobacco use screening for all adults, and cessation intervention (Ogundipe et al., 2015). Autism screening for children 16–24 months, behavioral assessments for children of all ages, developmental screening for children under age 3 years, and health surveillance throughout childhood promise to narrow future health disparities (USDHHS, 2014).

To enhance existing health services, the ACA allocates $295 million in formula-based supplement funding for 1195 community health centers (CHCs) on the mainland, Puerto Rico, US Virgin Islands, and the Pacific Basin. The funds will also facilitate the additional hiring of providers for oral health, behavioral health, pharmacy, and vision services for an estimated 1.5 million new patients nationwide (Institute for Healthcare Improvement, 2016; Kaiser Commission on Medicaid and The Uninsured, 2013; USDHHS, 2014).

To understand the impact of the ACA, it is important to understand rural communities and rural health disparities. The following section provides a brief overview of rural communities. For a detailed discussion on rural communities, see Chaps. 1and 2.

Rural Communities

A substantial percent of the American population reside in rural areas, such as communities, and have declined steadily with decrease in the social infrastructure – school, churches, small businesses, transit systems, and health facilities. Additionally, current rural trends, such as the restructuring of rural economies in which stable family agriculture jobs were replaced by low-wage service employment, increased migration of low-income urban racial/ethnic minorities and Hispanic and Latino immigrants to White small-town communities (Foulkes & Newbold, 2008), and shifts in the concentration of rural poverty have had a major impact on rural residents with disabilities (Smith, Humphreys, & Wilson, 2008).

Moreover, the lack of money, the unpredictability of income, the absence of affordable childcare, and the nonexistence of transportation have adversely affected rural communities. Rural areas also have high concentrations of low-income populations (Assistant Secretary for Planning and Evaluation [ASPE], 2012). One-quarter of the nonelderly rural population has a family income below the federal poverty level, about $19,790 for a family of three in 2014 (Ewoldt, 2014; Newkirk & Damico, 2014). Rural residents are more often uninsured compared to urban residents. Compared to their urban counterparts, they are also more likely to report their health status as fair or poor, experience restricted activity, and lack access to a primary physician (Bulger, 2010; Newkirk & Damico, 2014).

Impoverished rural communities are often "dumping grounds" for urban America (Strasser, 2003). For instance, economically declining rural communities have become home for America's prison population, hazardous and toxic waste sites, landfills, slaughterhouses, and commercial feedlots. Such forms of development often involve environmental injustice and racial discrimination issues (Smith & Tickamyer, 2011).

Health Disparities Coupled with environmental toxic health dangers, rural residents experience higher rates of chronic conditions, including diabetes, heart disease, and high blood pressure, as well as higher infant mortality rates. Indeed, morbidity and mortality rates, accidents, and occupational injuries are higher in rural areas compared to urban communities. Compared to urban residents, rural populations are more likely to experience inferior health outcomes after illnesses and injuries, cope with comorbidity, and develop a chronic illness at younger ages and experience poorer prognosis (Downey, 2013; National Center for Health Statistics, 2011). Moreover, rural communities lack mental health services and adopt a "mental health culture of silence" due to competing survival issues such as coping with unemployment, illnesses, and toxic environments and living in dilapidated housing with few community resources (Wilkinson & Blue, 2002; see Chap. 25).

Further, rural residents are more likely to report poorer health and experience restricted activity compared to their urban counterparts (Downey, 2013). Compounded by widespread poverty, high rates of unemployment-related health insurance, and fragile socioeconomic infrastructures, studies document that rural residents with disabilities have more problems with their health care than able-bodied counterparts. Using a qualitative research design, Iezzoni, Killeen, and O'Day (2006) described the impediments to health care in rural America and the way in which disabilities exacerbated barriers. The interviewees reported that the lack of transportation, the inability to find physicians that accept Medicaid coverage, and the stigma attached to disabilities impact their health-seeking behavior. Studies have confirmed that rural residents with disabilities experience more problems with their health care compared to non-disabled residents (Ogden Carroll, Kit, & Flegal, 2014).

Research Box 5.1: Rural Residents with Disabilities Confront Substantial Barriers to Obtaining Primary Care

Objective: To explore the health-care experiences of rural residents with disabilities in Massachusetts and Virginia

Method: A sample of 35 adults with sensory, physical, or psychiatric disabilities were recruited to participate in four focus group interviews. The interviews were transcribed verbatim to identify major themes.

Results: The interviewees reported significant barriers to seeking health care and emphasized that disability exacerbates the usual rural impediments to health care. As a result, they concluded that rural regions are less sensitive than urban areas to disability issues, in general, beyond health care. Themes identified as barriers to health care were (1) *difficulty finding caring and competent physicians*, (2) *the need for specialists and sophisticated services*, (3) *poverty and heavy reliance on Medicaid*, and (4) *the lack of physical access to health-care setting*. Local transit systems that specialize in door-to-door transportation services for the people with disabilities often fail. Although persons receive reservations, they are picked up hours early; transit services often fail to show up, and coordinating transit services with medical appointments also present problems. (4) *the need for advocacy and information resources*. Some interviewees emphasized that limited housing and inadequate resources to renovate existing housing and public buildings to improve access characterized their communities. They also stated that their socioeconomic status and lack of medical insurance as well as physician's refusal of Medicaid coverage complicate the health-care services received. Often interviewees reported that the cost of prescription medications and the high price of assistive technologies, such as power wheelchairs, uncovered by insurance caused additional stress and reduced health-care utilization.

Conclusion: Rural residents with disabilities report similar health-care access difficulties as their nondisabled rural counterparts. However, sensory, physical, and psychiatric disabilities as well as persons with disabilities' long-term relationship with the health-care system present additional challenges.

Questions:

1. What are some of the primary barriers to obtain primary care for rural residents with disabilities?
2. What are some of the travel barriers to health providers for rural residents with disabilities?
3. Why do you think the interviewees reported that rural regions are less sensitive than urban areas to disability issues, in general, beyond health care?

Note: Adapted from Iezzoni et al. (2006)

Even after achieving access to medical care, people in rural communities with disabilities are often less likely to receive quality and aggressive medical treatment in comparison to their urban counterparts. For instance, compared to urban communities, patients with pneumonia who live in rural neighborhoods are less likely to receive appropriate pneumonia care. The wait time for a kidney transplant is longer for rural patients living in zip codes with a high proportion of poverty compared to low-income urban zip codes (O'hare, Johansen, & Rodriguez, 2006). Furthermore, pharmacies located in rural communities are less likely to stock sufficient medications to meet community needs compared to those in urban areas (Wilkinson & Blue, 2002).

Rural children with disabilities also confront health disparities (Doty et al. 2014). They experience higher mortality rates between ages 7 and 19 than their urban counterparts (Annie E. Casey Foundation, 2016). Research has reported that deaths from motor vehicle accidents and firearm injuries are higher among rural children compared to children in urban communities (Berthold & Libal, 2016; Hill, Moloney, Mize, Himelick, & Guest, 2011). Mexican children who live in rural areas also confront health disparities. They are 2–3 times more likely to have poor or fair health as opposed to good or excellent health, compared to non-Mexican children. Intestinal parasites, nutritional deficiencies, dental problems, diarrhea, exposure to pesticides, and continuous cycles of otitis media, leading to hearing loss, are frequently reported among rural Mexican farmworkers' children compared to Mexican rural nonfarmworkers' children (Becker Herbst & Gonzalez-Guarda, 2016; Berthold & Libal, 2016).

Structural Barriers and Rural Health

Rural residents with disabilities experience structural barriers, which prevent them from adequate health care (USDHHS, 2014). For example, rural clinics often lack ramps to access facilities, which discourage clinic visitation. They also confront insufficient space for wheelchairs, canes, and walkers; and long distances to health-care services prevent utilization. Mountains, ravines, valleys, rivers, unpaved roads, and steep hills also often pose transportation difficulties. The absence of transportation services, as well as poor roads, and the lack of parking negatively influence access to rural health services. Public transportation, private taxis, or special taxi services and medical transport vans are frequently inaccessible in rural communities. Therefore, often rural residents fail to attend scheduled medical, dental, or eye appointments. (See Chap. 3 for detail discussion of rural transportation.)

Other barriers also impeded access to rural health care. For instance, the lack of assistance for persons with low vision and the absence of health-care workers proficient in sign language and various bilingual services are major barriers to health-care utilization in innumerable rural communities (Hansen & Donohoe, 2003). Further, small rural hospitals are at risk of closure due to financial deficits, which limits rural resident access to diagnostic procedures, ambulance services, and emergency room care. The following are other factors that often discourage rural residents with disability to seek health care: (a) lack of service providers and recruitment and retention of service providers, (b) absence of latest medical diagnostic equipment and poorly trained health-care providers, and (c) fragmented health service delivery systems. Further, hospice utilization is also lower in rural neighborhoods than that of urban communities, which may reflect a fragmented nursing home system (Virnig, Moscovice, Durham, & Casey, 2004). Compared to urban areas, rural nursing homes often have a lower staffing ratio, inspection deficiencies, and greater financial vulnerability (National Rural Health Association [NRHA], 2005, 2007). Therefore the ACA has an additional significance given rural health-care services and delivery systems.

ACA Implications for Rural People with Disabilities

There are a variety of health provisions within the ACA that affect health services in rural areas, both through general provisions of the law and through measures that are specifically designed to health-care networks that serve rural populations. Under ACA, rural Americans will no longer worry about losing coverage if they're laid off or change jobs. They will have access to preventive care, such as mammograms and other cancer screenings. ACA also makes a significant investment in state and community-based efforts that build the health-care workforce, promote public health, prevent disease, and protect against public health emergencies. Further the ACA has changed the culture of health care from a treatment-based approach to that of health prevention, public health and education, and a family-centered approach.

To assist individuals with disabilities in rural communities in seeking health care, ACA's provisions strengthen primary care through Medicaid expansion coverage to include incomes up to 138% less than or equal to the poverty level (Collins et al. 2015). Thus, rural residents with a chronic disease and people living with HIV may receive housing, childcare, and nutritional support, in addition to prevention services (Hamel, Blumenthal, Adams, & Nuzun, 2015; Minow, 2012).

The ACA also includes provisions to benefit rural-employed residents with disabilities. These include the establishment of new organizations for workforce planning, supporting existing organizations, health-care workforce recruitment targeting underserved communities and development, grants, loan repayment programs, and various training and education mechanisms (White House Fact Sheet, 2012). Specifically, rural young people with disabilities can enroll in college loan repayment programs. Currently, the ACA funds several demonstration projects to assess effective and innovative models for delivering high-quality and cost-effective patient-centered care (USDHHS, 2014; Vincent & Reed, 2014).

Moreover, rural working-age individuals with disabilities are often live in poverty to maintain Medicaid coverage. Importantly, Medicaid expansion coverage does not limit assets to determine eligibility. Consequently, expansion coverage allows greater asset accumulation and better quality of life and avoids lifelong dependence on disability programs (Beronio, Glied, & Frank, 2014; Blumenthal & Collins, 2014; Jost, 2014; Mechanic, 2012).

Through the ACA, rural individuals are more likely to receive timely and well-organized health services that emphasize prevention and chronic care management. The Center for Medicare and Medicaid Innovation (CMMI) has been established to conduct innovative payment and delivery system models that improve the quality of care in Medicare, Medicaid, and the Children's Health Insurance Program (CHIP), while slowing the rate of cost (APHA, 2014; Ewoldt, 2014). For example, The Center for Chronic Care, (CCC) in Livingston, New Jersey, is one such entity. It is vastly different from an urgent care service, which stabilizes very sick patients and sends them to the hospital. Instead, the goal of the CCC is to avoid rehospitalization and stabilize high-risk patients to counteract an exacerbation of their illnesses. Therefore patients receive longer consultations and may be seen multiple times. Nurse care managers, social workers, nutritionists, and clinical pharmacists stabilize the patients' condition, improve their quality of life, and teach them self-management skills they can apply in their home environment (Chronic Care Center Opens in Livingston|Summit Medical Group, 2016).

The ACA is to be applauded for its focus on mental health; however, individuals in the early stages of behavioral health conditions are a new priority population (Saloner, Bloner, & Le Cook, 2014). Under the Medicaid expansion of the ACA, individuals experiencing their first episode of psychosis can benefit from early treatment and prevention services (Beronio et al., 2014; Buck, 2011). Prior to the implementation of the ACA, most of them could not qualify for Medicaid because they did not qualify for Supplemental Security Income (SSI), as they were not significantly disabled at this early phase of a psychotic illness. Under the ACA, single able-bodied adults can qualify for Medicaid based on income without qualifying for SSI (Blumenthal & Collins, 2014). In addition, some early psychosis patients will be able to remain on parents' health insurance for longer because of ACA; others will qualify for health insurance on the exchanges without fear of being disqualified based on psychosis as a preexisting condition. Moreover, the ACA law safeguards rural citizens against insurer's practices of preexisting condition discrimination. Studies show that rural populations experience a higher percentage of preexisting conditions and chronic diseases (Hartley, 2004; Huntington et al., 2011; Izzoni et al., 2006).

Table 5.1 provides a list of provisions that impact rural residents. The way in which these provisions affect the delivery of health services is determined by service providers, who and where the patient is, and what type of health-related service is sought.

Limitations of the ACA to Rural Communities

Consistently, critics accused that President Obama's Affordable Care Act is a government control of the health-care system. Such criticism is unwarranted and unfounded. As the law stands, the architects of ACA decided to be lenient, which may contribute to its demise. Two major issues surfaced that could undermine the law's fundamental logic.

First, the enrollment of large numbers of people in private insurance plans has been a major challenge. For the marketplaces to succeed, it

Table 5.1 Essential health benefits and the Affordable Care Act

Creating new coverage options for individuals with preexisting conditions: Under the new law, insurance companies are already banned from denying coverage to children because of a preexisting condition. In 2014, they are banned from discriminating against anyone with a preexisting condition such as cancer and having been pregnant
Covering preventive services with no deductible or co-pay: Under the new health-care law, all Americans joining a new health-care plan must be able to receive recommended preventive services, such as cancer, diabetes, and blood pressure screenings, with no out-of-pocket costs such as co-pays or deductibles
Removing limits on health benefits: The law bans insurance companies from imposing lifetime dollar limits on health benefits – freeing cancer patients and individuals suffering from other chronic diseases from having to worry about going without treatment because of their lifetime limits. The new law also bans annual limits
Scrutinizing unreasonable premium increases: In every state and for the first time ever, insurance companies are required to publicly justify their actions if they want to raise rates by 10% or more. And an increasing number of states have more power to block unreasonable premium increases from taking effect
Providing new coverage for young adults: Insurance companies are now required to allow parents to keep their children up to age 26 on their insurance plans
Costs and increasing coverage: Affordable insurance exchanges are one-stop marketplaces where consumers can choose a private health insurance plan that fits their health needs
Decreasing costs for seniors on Medicare: Under the new law, seniors can receive recommended preventive services such as flu shots, diabetes screenings, as well as a new Annual Wellness Visit, free of charge
Providing better value for premium dollar through the 80/20 rule: Under the new health-care law, insurance companies must provide consumers greater value by spending generally at least 80% of premium dollars on health care and quality improvements instead of overhead, executive salaries or marketing. If they fail to do so, they must provide consumers a rebate or reduce premiums
Increasing access to community health centers: The Affordable Care Act increases the funding available to more than 1100 community health centers in all 50 states to double the number of patients they served from 19 million to nearly 40 million by 2015. Health centers have received funding to create new health center sites in medically underserved rural areas
The new health-care law includes new resources that would boost the number of doctors, nurses, and health-care providers in communities where they are needed in rural communities

Note: Adapted from Bagley and Levy (2014)

will be necessary for millions to sign up and enough healthy people to pay into the system to offset the medical costs of those with higher medical needs and health-care costs.

The Department of Health and Human Service announced that the number enrolled tripled in November of 2015; approximately 11.4 million people signed up for ACA coverage (APHA, 2014). The tally includes people who signed up for the first time and existing consumers. Some 8.6 million signed up through the federal exchange, which is handling enrollment for 37 states and 2.8 million in the state-based exchanges (Blumenthal et al., 2015). Florida and Texas, which have high rates of uninsured, each had more than one million people, select health plans on the federal exchange, (healthcare.gov) (Blumenthal & Collins, 2014). Their Republican governors were among the many who opposed ACA (Beronio et al., 2014; Minow, 2012).

The enrollment hinges on one critical policy – the often-attacked individual mandate, which requires that everyone in the country have health insurance by March of 2014 or pay a fee. Unfortunately, the mandate is weak. The penalty for lacking coverage next year is a mere $95; and it may be difficult for the Internal Revenue Service to collect from some people. Healthy people might choose to forgo 12 months of premium payments and elect to pay the much smaller annual fee. A larger fee, which was in early drafts of the law, would have been a more effective incentive (Drew, 2011; Huntington et al. 2011).

Major insurers are pulling out of ACA because disproportionately sicker risk pools are expensive to cover, resulting in huge insurers' financial losses. To offset those losses, insurers have increased premiums, making coverage less affordable for the relatively healthy consumers – including millions who receive taxpayer subsidies through the law. As insurance companies' costs skyrocket, younger, healthier people will either walk away from the law or avoid enrolling (Minow, 2012; Newkirk & Damico, 2014).

Enrollment in the exchanges is influenced by each state's decision. The states that have not expanded Medicaid have left 5.7 million of the nations' poorest citizens without coverage options. States that refused participation in the expansion coverage are more likely to have increased numbers of the uninsured, low-income, and unemployed individuals who live in rural southern communities (Blumenthal & Collins, 2014).

The second alarming limitation is that insurance companies may dissuade individuals from enrolling in their plans (Farley, 2010). Before the Affordable Care Act, insurers rejected applications from people with preexisting conditions. Now that it is illegal to reject individuals with preexisting conditions, some insurance companies may find it more economical to discard enrollees. For example, often insurers limit access to important pharmaceuticals, such as HIV medications to push rural ill patients away; they are also refusing high-risk patients and elderly rural patients (Farley, 2010; Haeder & Weimer, 2013).

The lack of funding for major provisions is also a limitation of the ACA. For example, it is well known that rural communities often lack financial resources to attract and sustain health-care providers for residents with disabilities. Per the Institute of Medicine, 2011, the sustainability of a quality rural health workforce is one of the most crucial issues in the twenty-first century. However, the National Care Workforce Commission established by the ACA to recruit, train, and retrain *remains unfunded*.

Despite the ACA's focus on direct care workers, it fails to address the quality of care from institutional to home and community as well as hospital-based care and negates the increased demand for home care, given closures of rural hospitals. Further, because one in five Americans will be older than 65 by 2030, experts believe that the aging of the population will place strain on home health-care delivery systems in rural communities (Weitz, 2000).

The inadequate supply of a home-based workforce has prevented transition from nursing home residents to home-based settings. For example, if The Community Living Assistance Services and Supports (CLASS) voluntary insurance program had been implemented, young people in rural communities could have relied on home care and created additional employment for rural home health workers. Unfortunately, CLASS has not been implemented, and there is no date as to its implementation. On October 14, 2011, HHS Secretary Kathleen Sebelius announced that the Obama Administration would not attempt to implement the CLASS Act stating "I do not see a viable path forward for Class implementation at this time"(Spoerry, 2011). On January 1, 2013, the CLASS Act was officially repealed as part of the American Taxpayer Relief Act of 2012, known as the Fiscal Cliff Bill. This law contains a provision that repeals the Community Living Assistance Services and Supports (CLASS) Act. Republican opponents of the plan called it "a financial gimmick" to manipulate the Congressional Budget Office deficit projections, while Democratic Senator Kent Conrad called it a "Ponzi scheme" (Spoerry, 2011).

Moreover, ACA fails to address quality of health-care training, transportation issues, high cost of prescriptions, and lack of home health service providers. Additionally, although family psychosocial education, skill training, supportive community entities, and employment have been effective in treating mental illnesses, they are not covered by Medicaid.

Finally, the most important and glaring problem of the ACA is the preservation of the for-profit motive of the US health-care system. Within the health-care system, physicians, hospitals, and pharmaceutical and medical supply companies are pressured to generate profits. Similarly, to survive, insurers will retain the for-profit motive. Thus, insurers seek healthy members to avoid high medical costs. As a result, people with disabilities in rural communities are less likely to be uninsured since insurers continue to avoid enrolling individuals with high medical risks. Consequently, rural people with disabilities will continue to lack access to health care and cope with health disparities (Murguia, Peterson,

Table 5.2 Myths associated with the Affordable Care Act

The ACA will increase the national debt: The ACA greatly increases the national debt. However, estimates by the nonpartisan Congressional Budget Office suggests that the law decreases the national debt
Myth 2. American taxpayers pay for free health-care coverage for undocumented immigrants: The laws do not provide free care for non-US citizens
Myth 3. Small business will be hurt: Only businesses with more than 50 employees are required to provide insurance coverage and contribute to its costs or pay a fee. State-based insurance exchanges will help with employee insurance coverage for businesses that have fewer than 100 employees. For businesses with fewer than 25 full-time employees, employers may use a tax credit to offset the cost of providing health care
Myth 4. Individuals will not be able to make their own end-of-life decisions: There has been much talk about ACA ration health care through “death panels” which limit end-of-life care that older adults receive. The ACA provides payment for physicians who engage in end-of-life counseling with patients who request it. *Even though this provision has been eliminated, still 40% of the population worries that a government panel will be making decisions about end-of-life care for Medicare recipient that will result in rationing*
Myth 5. The federal government will control health care: The ACA is a “government takeover” of health care, with a move toward socialism. On the contrary, the ACA calls for states, insurers, and private health-care providers involve to improve both access and efficiency of health care

Note: Adapted from Sorrell (2012)

& Zea, 2003). Additionally, ACA confront an uphill battle since misinterpretation of the legislation has distorted public opinion, and many myths still plague the law. Table 5.2 shows myths associated with the ACA.

Improving Service Delivery to Rural Residents with Disabilities

Several provisions in the ACA improve health care for persons with disabilities in rural communities, including emphasis on patient education and community clinics, strengthen Medicare and Medicaid, and placing greater emphasis on preventive care and mental health. However, various organizations are calling for a broader perspective of health rather than a narrow definition of specific programmatic changes. For instance, in 2015 Robert Wood Johnson (RWJF) – the nation’s largest health philanthropy – advocated a “culture of health” to form a framework to tweak ACA. RWJK (2015) reasoned that it is insufficient to pronounce a war on disparities and convince the public and political leaders. A culture of health philosophy replaces the elimination of health disparities ideology to “a culture of health.” A culture describes the societal values expressed in the American health system, including the environmental, economic, and social forces that impact health (Eckersley, 2006).

Based upon extensive analysis of the field, RWJF (2015) identified four areas where action is needed to build a culture of health (Bulger, 2010). First, a new culture requires combined efforts of private, social, and public sectors, silos that exist within the health-care system as well as private and social sectors. For example, a study found that the Philadelphia libraries are visited disproportionately by vulnerable populations and that in 2015 a half million of those visits were for programs designed to address social determinants of health (Murray, 2008). Although libraries cannot solely provide health education, cross-sectoral partnerships such as the library churches and community centers can provide a health hub in vulnerable communities (Minkler, 2000).

Second, a culture of health suggests that the characteristics of living spaces have a direct effect on health. Researchers have focused on well-being, a concept that captures domains such as satisfaction with one’s community and the character of one’s work relationships (Plough, 2014; Porter, 2009). Indeed, population well-being is associated with life expectancy, even after race, poverty, and education are controlled. However, various cultural definitions of well-being exist. For example, research has found a correlation between neighborhoods’ high collective efficacy – measured as residents’ reporting that people “get along and help each other”; the absence of domestic, gang, and police violence are also characteristics of cultural-specific well-being (Billings & Blee, 2000). Culture of health advocates argues that rather than focus on medical treatments, health policy-makers should emphasize factors that improve various perspectives of well-being (Eberhardt & Pamuk, 2004).

Additionally, to replace the ACA, policymakers are focusing on initiatives to improve health through social interventions, which tweak and expand ACA. The Nurse-Family Partnership Program (NFP) is an example of a health-care program that involves a holistic view of health needs, health, social, and individual and family. For instance, Olds (2002) revised the traditional home nurse concept to focus on low-income adolescents with no previous births. Women in the intervention group received nurse home visits, during pregnancy and the first 2 years of the lives of children. Women in the intervention group also received family support and the needed health and human services. Evaluation of the NFP demonstrated that it improved prenatal health-related behavior, pregnancy outcomes, and lower levels of pregnancy-induced hypertension, suggesting that family support and social services enhanced health and reduced pregnancy-related complications.

The results of the recent federal and statewide elections sent a clear message that significant changes in the direction of health policy are on the horizon. Greater emphasis will likely be placed on Health Savings Accounts [HSA] and, perhaps, relatively less on payment reform. Indeed, following the election of President Donald Trump, key industry groups that supported Obamacare indicated that President Trump's replacement bill, known as the American Health Care Act (AHCA) harmed vulnerable populations. President Trump has proposed expanding tax-free health savings accounts, selling insurance across state lines, block-granting Medicaid, and giving tax credits to people to help affordability. However repealing Obamacare, and the subsidies, will result in approximately, 14 million people would lose Medicaid and Children's Health Insurance Program coverage; and 18 million people would lose their individual (non-employer) coverage, for a net loss of 22 million insured. Moreover, the system delivery provisions in the ACA will be eliminated.

It is unwise to speculate about the components in the AHCA because of what is being proposed can change drastically in rewrites and modifications. Substantial opposition does exist to the bill. For example, the American Medical Association stated ".. . we cannot support the AHCA as drafted because of the expected decline in health insurance coverage; and the potential harm it would cause to vulnerable patient populations" (Lee, Collinson, & Murray, 2017).

Because negative messages about Obamacare have outnumbered positive messages, 15 to 1 people are unaware of the benefits associated with the ACA. Even 3 years after its approval, 54% of Americans opposed the Act, which caused President Trump to repeal and replace it. In sum, ACA improves the health-care system for rural residents living with disabilities and provides affordable health insurance to all Americans. It reformed practices of insurance companies to ensuring better quality health care. Time will tell if the objections of the ACA will moderate and create the kind of broad public support for the ACA that Medicare and Medicaid – also controversial when they were passed – now enjoyed.

Summary

In 2010, following a contentious debate, the US Congress passed significant health-care reform legislation – the Affordable Care Act. The legislation is projected to bring health insurance to an additional 32 million persons over the next several years and modify the health-care system. The current literature clearly demonstrates that the ACA has led to expansion in insurance coverage and improved access to care for the relatively poor, less healthy populations, and minorities. Moreover, in the aggregate, health-care expenditures have moderated. Residents in rural areas have benefited from the ACA through increased health-care rights and protections and expanded access to affordable quality health care to millions of uninsured. Provisions to protect consumers in rural communities with disabilities include insurance companies no longer being able to deny individuals for preexisting conditions or being able to drop their coverage for being sick, free preventive treatments, the elimination of discrimination, and annual and lifetime limits on essential health benefits. Obama's health-care plan overhauls Medicare as well as increasing benefits, expanding coverage, fighting fraud, cutting costs, and improving care for patients in general and for rural residents with disabilities, specifically.

Learning Activities

Self-Check Questions

1. What are the major service delivery and insurance reform provisions in the Affordable Care Act?
2. What social conditions were prevalent during the creation of the ACA?
3. What are the challenges of the ACA to improve the health of rural, frontier, and territory residents living with disabilities?
4. What are the limitations of the ACA?

Experiential Exercises

1. Interview a young (between the ages of 30 and 40) and an older recipient (aged 50 and older) of the ACA in a rural, frontier, or territory community to determine their experiences and perceptions of the ACA. Determine the evaluation of the ACA as it relates to service delivery, quality of care, as well as access to care. Compare their views of ACA.
2. Visit a Medicaid/Medicare office to interview a human service provider in a rural, frontier, or territory community to determine their experiences with ACA. Determine the person's evaluation, challenges, and limitations of ACA. In conducting the interview, use open-ended questions, such as the following:
   (a) Tell me about your experiences with Medicaid/Medicare clients before ACA.
   (b) Discuss your experiences with Medicaid/Medicare clients after ACA.
   (c) If you could change ACA, what changes would you make?
   (d) Tell me your thoughts regarding the ACA.

Be sure to thank the interviewee for his/her time. Write a paper on the results of your interview.

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Ethical Vocational Rehabilitation Practice and Dual Relationships in Rural Settings

6

Melissa Manninen Luse

Learning Objectives
Upon completion of this chapter, the reader will be able to:

1. Describe the characteristics of rural settings that make for ethical dilemmas regarding dual relationships.
2. Understand relationships and confidentiality.
3. Define dual relationships as according to the CRCC Code of Ethics.
4. Define confidentiality and privacy as according the CRCC Code of Ethics.
5. Discuss the ethical dilemmas around dual relationships rehabilitation counselors face in rural and small town settings.
6. Understand issues of rural and small town settings.
7. Discuss the ethical dilemmas around confidentiality and privacy rehabilitation counselors face in rural settings.
8. Discuss ethical models rehabilitation counselors can use to evaluate and work through ethical dilemma.

M. Manninen Luse (✉)
Rehabilitation and Human Services,
The Pennsylvania State University,
University Park, PA, USA
e-mail: mml27@psu.edu

Introduction

Rehabilitation counselors in rural and small town settings are likely to face complex ethical dilemmas regarding dual relationships and confidentiality and privacy (Malone & Dyck, 2011). These dilemmas are due to the multilayered environmental, cultural, social, and psychological factors that come with living and working in rural areas (Malone & Dyck, 2011). Rural communities are often geographically isolated and have lower population densities, resulting in limited employment opportunities, healthcare and human services and providers, public transportation, and childcare options (Dyck & Hardy, 2013; Malone & Dyck, 2011). Rural areas are also disproportionately affected by loss of industry, environmental changes, and natural disasters (Chipp, Johnson, Brems, Warner, & Roberts, 2008). Rural and small town communities often struggle with difficulties in accessibility of available services, long wait times, lack of information, potential for lost work time, and accessing available providers who may not be the most appropriate (Dyck & Hardy, 2013). Aside from availability, rural cultural norms, stigma, and lack of anonymity may prevent people from accessing services (Dyck & Hardy, 2013). Cultural norms often include value for self-reliance and hardiness, which can perpetuate stigma associated with disability and prevent people from seeking help. For example, in a

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study on the help-seeking behaviors of farmers in Canada, cultural norms of pride and independence were found to be the most significant factors for why people did not seek mental health services (Dyck & Hardy, 2013). Furthermore, some rural settings, such as Native American or first-generation immigrant communities, finding culturally appropriate services, have been found to be the major issues that hinder people from seeking services (Dyck & Hardy, 2013).

This chapter will be a discussion of the importance of understanding dual relationships in rural and small town communities and confidentiality and privacy. We will use the Code of Professional Ethics for Rehabilitation Counselors (2010) as a framework to examine dual relationships and common challenges rehabilitation counselors face in rural settings. While rehabilitation counselors are often trained to not participate in dual relationships, this may not be possible in rural communities. Rural areas are small, often with tight-knit communities. Therefore, it can be unavoidable for rehabilitation counselors and clients to have intersecting connections and overlapping roles. Rehabilitation professionals may struggle with how to preserve boundaries both personally and professionally and maintain confidentiality and privacy of clients. These overlapping roles can also affect treatment boundaries. To be successful in a rural area, rehabilitation professionals may be expected to be highly active within the community they serve, participating in various community and religious activities, and serve on various community boards and many of the same activities in which clients may also participate.

We will first examine dual relationships and discuss what they are, what are the characteristics of rural and small town communities that foster the likelihood of dual relationships, what do the Code of Professional Ethics for Rehabilitation Counselors (2010) and the literature have to say about dual relationships, and what are the benefits of dual relationships. We will then discuss ethical dilemmas regarding confidentiality and privacy, examining the role of continuing education and supervision in supporting ethical practice, and the pros and cons of technology to manage ethical dilemmas. Strategies to manage dual relationships and protect confidentiality and privacy will be provided. We will wrap up the chapter by examining two ethical models rehabilitation counselors can implement in practice: Herlihy and Corey's decision-making model and Tarvydas integrative model for ethical behavior.

Characteristics of Rural Setting that Create Dual Relationships

Rural and small town communities share many similar cultural norms making rural communities unique as well as create for the likelihood of dual relationships. Furthermore, according to Nelson, Pomerantz, and Bushy (2007):

> rural communities are unique not just because of their small population density or distance from an urban setting, but also because of the combination of their social, economic and geographical characteristics as well as their residents' cultural, religious and personal values. (p. 137)

Three important characteristics of rural communities that can lead to dual relationships include the limited availability of services, cultural and personal values, and hesitancy to seek outside services. Let's look at each of these a little closer.

Limited Availability of Services

Rural communities face significant shortages of services and providers, as well as geographic and transportation barriers that can hinder a person's ability to seek services (Cates, Gunderson, & Keim, 2012; Nelson et al., 2007). Added to this mix is the fact that rural community members face higher likelihood of not only health issues and risk for disability in general but are more likely to live with severe conditions and have more profound needs than their urban counterparts. Rehabilitation counselors working in these communities are therefore likely to work with not only fewer resources but be faced with the high probability of managing dual relationships as they are going to have to rely heavily on community leaders and family and friends to help support the client.

Cultural and Personal Values

Rural communities have cultural values which can affect perceptions of healthcare and counseling services and help-seeking behaviors (Chipp et al., 2008). These values that can particularly affect decision-making include:

- Increased sense of self-reliance and self-care
- Strong work ethic that can hinder a person's willingness to take time off from work and focus on one's health
- Increased reliance on informal supports (i.e., family, neighbors, church, and other community groups)
- Strong sense of community ties and interdependence on one another to provide informal support (Cates et al., 2012; Chipp et al., 2008; Nelson et al., 2007)

Hesitancy to Seek Outside Services

People can be hesitant to seek services outside of one's community due to distance, transportation issues, and environmental and climatic barriers such as mountain ranges or weather conditions. Hesitancy to seek outside resources can also be due to the inability or even unwillingness of family and friends who are likely to provide main forms of support to travel long distances (Cates et al., 2012). Additionally, due in part to self-reliance and community interdependence, people can be reluctant to seek services in another farther away and unfamiliar location. This reluctance and unfamiliarity of outside communities and providers can create distrust of people outside of one's community or even providers new to the area. A long-time rehabilitation counselor in the community can be faced with the conflict of how to persuade a person to seek the needed treatment. Other and potentially very serious issues can arise if a rehabilitation counselor is not able to persuade a client to work with another provider, especially if the provider is outside of the area. Clients may be left with inferior care, the potential for worsening of health, and inappropriate services that may not only hamper health but also affect one's participation in employment, education, and activities of daily living. Furthermore, the counselor can be faced with legal or licensure issues when faced with such an issue and is asked to potentially practice outside their scope of competence. New rehabilitation counselors, especially those new to a community, may also be seen as outsiders (Halverson & Brownlee, 2010). Community members may be very hesitant and distrustful of a new counselor. Counselors may find themselves being faced with dual relationships, as the likely way they may be able to have consumers seek them out and gain trust is through community involvement and getting to know people on a more intimate level.

Rehabilitation counselors must recognize the need for developing an in-depth cultural awareness of the community they serve, which will include issues around dual relationships including confidentiality and privacy, the likelihood of developing dual relationships, and the benefits and risks of dual relationships. Chipp et al. (2008) in their study of ethical dilemmas faced by rural providers found that the smaller the community a provider works in, the more likely that provider recognizes the need to seek the support of community leaders and elders as well as involves the family to provide support to clients. Providers also reported the need to rely on community leaders to learn about the culture of the area as well as effective strategies to work in the culture and ways to adapt one's practices and access or develop effective and culturally appropriate resources.

Dual Relationships

Rehabilitation professionals working in rural communities are likely to encounter frequent potential instances of nonprofessional, or dual, relationships with clients. Therefore, according to Schank, Haldeman, Helbok, and Gallardo (2010), "the issue becomes how to handle dilemmas and overlap, rather than how to avoid them" (p. 503).

Dual relationships are defined as overlapping informal relationships between the rehabilitation counselor and client, outside of the therapeutic relationship (Malone & Dyck, 2011). Dual relationships can "before, during, or after the professional relationship, and arise either by choice or by chance" (Malone & Dyck, 2011, p. 207). Dual relationships may be low or high risk.

Low-risk dual relationships are overlapping relationships or *boundary crossings*, which may be common, may be non-harmful, and may even be beneficial (Malone & Dyck, 2011). These low-risk situations are most likely to occur where the counselor both lives and is active in the community in which a person works (Malone & Dyck, 2011). For example, these interactions can occur in grocery or department stores, church, and social events, and other common situations where incidental contact can occur between counselor and clients. According to Malone & Dyck (2011), low-risk boundary crossings can also include "home and community visits to clients, or other minor deviations from a strict professional role" (p. 207). Malone and Dyck go on to state that to ensure nonmaleficence, professionals must "perceive all non-office or nonprofessional relationships as potentially risky" and "use appropriate self-disclosure" and discuss risks and benefits with clients (p. 207).

High-risk dual relationships are called *boundary violations* (Malone & Dyck, 2011). These high-risk relationships have the potential to be much more problematic as they include complex situations such as working with colleagues, family members, current and former intimate partners, business and community relationships, leisure activity affiliations such as sports leagues, or situations in which children of both parties are friends. These high-risk relationships have a significant potential to be damaging not only to the client but also to the counselor and to the rehabilitation counseling profession itself.

Dual Relationships: Intimate and Nonprofessional Relationships

The Code of Professional Ethics for Rehabilitation Counselors (from here on referred to as the Code) sets the standards to ensure rehabilitation counselors act in an ethical manner. However, the Code provides broad-based guidelines to cover a wide range of situations to assure ethical behavior. It does not explicitly address dilemmas many counselors, such as rural rehabilitation professionals, are likely to face. Regarding dual relationships, the Code conflicts with what may actually occur in practice for rural counselors. The Code states: "Rehabilitation counselors avoid nonprofessional relationships with clients, former clients, their romantic partners, or their immediate family members, except when such interactions are potentially beneficial to clients or former clients" (Standard A.5.d). To be able to effectively work through issues related to rural cultural values, be viewed as a part of the community, and handle dual relationships, rural counselors are likely to find themselves in situations that rub against the Code and standard ethics training (Cates et al., 2012). Standard A.5 of the Code does discuss generalized acceptable and unacceptable roles and relationships with clients that professionals can interpret to fit to their particular situation. However, five out of seven parts of Standard A.5 discuss intimate relationships with clients:

1. Prohibition of sexual or romantic relationships with current clients
2. Sexual or romantic relationships with former clients
3. Prohibition of sexual or romantic relationships with certain former clients
4. Nonprofessional interactions or relationships other than sexual or romantic interactions or relationships
5. Prohibition of counseling relationships with former romantic partners

While the issue of intimate relationships with clients is a serious issue, rural rehabilitation counselors are likely to face more problems with non-intimate dual relationships. Let us examine some of these issues rehabilitation counselors may face in more detail and how certain characteristics of rural settings can lead to dual relationships. Let's begin with intimate relationships.

Intimate Relationships The Code prohibits counselors from engaging in sexual or romantic relationships with current clients (Standard A.5.a) and states that counselors should avoid such relationships with former clients or their former romantic partners or family members for at least 5 years (Standard A.5.b). Even after 5 years is up, the Code states that counselors must "give careful consideration to the potential for sexual or romantic relationships to cause harm to former clients. In cases of potential exploitation and/or harm, rehabilitation counselors avoid entering such interactions or relationships" (Standard A.5.b). The Code is very clear that counselors are not to engage in an intimate relationship with a former client who has "a history of physical, emotional, or sexual abuse or if clients have ever been diagnosed with any form of psychosis or personality disorder, marked cognitive impairment, or if clients are likely to remain in need of therapy due to the intensity or chronicity of a problem" (Standard A.5.c).

While it should be common sense for rehabilitation counselors to not engage in intimate relationships with clients, this is a significant issue in practice and the number one cause for the filing of formal complaints (Understanding Counselor Liability Risk, 2014). According to the most recent Healthcare Providers Service Organization (HPSO) Report (Understanding Counselor, 2014), "the most frequent professional liability allegations asserted against counselors involve inappropriate sexual/romantic relationships with clients or the partners or family members of clients" (p. 9).

While intimate relationships with clients, former clients, or family members can pose a serious problem, it can become even more complicated in rural and small town settings. In rural settings, the avoidance of intimate relationships with clients or their family members may prove to be very complex where there are limited choices in the selection of intimate partners or intimate partners who may not be related to or well acquainted with clients. For example, a counselor may begin an intimate relationship and find out that the new partner is related to a client. However, the Code does not address how rural counselors should navigate such complexities. Nor is there much research and literature on the complexity and navigation of counselor-client intimate relationships.

Nonprofessional Interactions Rehabilitation counselors working in rural communities will find it very difficult to avoid at some level dual relationships with current and former clients or their families. The only realistic way to avoid such situations is to avoid all human contact. Counselors are likely to attend the same religious organizations, shop at the same stores, or even be provided a business service by a client or a client's family member. For example, a transition rehabilitation counselor may work with the teenager of the only service garage owner in the area. If the counselor's car is in need of repairs, it cannot be expected that the counselor is to go out of the way to find another garage. Or, a rehabilitation counselor who covers a whole county may provide services to the only plumber or electrician in the counselor's community, services that the counselor at some point likely to require and may not have other options for several miles. The rural rehabilitation counselor is also likely to cover a whole county or large region, with few other resources and providers to work with and provide to referrals. The rehabilitation counselor may be expected to provide a wide variety of services to the community including vocational counselor, mental health provider, resource provider to locate and access other health and human services, as well as consultant to other health providers. Additionally, as previously discussed, in some communities for a counselor to be welcomed into a community and trusted, it may be expected that the individual participate in certain activities and organizations where the likelihood of running into clients or gaining referrals will occur.

Other examples of situations rural counselors may experience that could result in dual relationships include (adapted from Schank et al., 2010, p. 503):

- A counselor who works for the local small college provides multiple student affair services including general and career counseling and disability services.

- A Native American counselor may have frequent out-of-therapy contact with clients and their families and may collaborate with local helpers and healers.
- A sport and faith-based counselor may attend events where clients are usually present.
- A counselor who is fluent in American Sign Language and also a chemical dependency provider may socialize with clients and family members of clients within their small communities.
- A counselor who is gay and is active in local LGBTQ community organizations may be sought for therapy precisely because he is visible within their own small community.
- A counselor who wants to support local businesses within her community must then deal with the strong possibility of business transactions with current or former clients and the families of those clients.

Related to Schank and colleagues' example is that when seeking out therapy, people are likely to *self-match* with a counselor, to seek out a counselor that "shares their attitudes, race, education, social class, and/or religion" (Gonyea, Wright, & Earl-Kulkosky, 2014, p. 125). People "feel more comfortable discussing their lives and presenting issues when they believe their therapist holds the same values or shared cultural experience" (Gonyea et al., 2014, p. 125). Gonyea and colleagues suggest that self-matching may be more likely in rural settings where people are more inclined to not trust outsiders and therefore may be more likely to seek out counselors who belong to the same circles as them. Self-matching can become even more complex when the therapist belongs to a minority population. "In addition to the limited number of available therapists in a small community, there are far fewer minority therapists in general. Therefore, when minority clients attempt to self-match, there is a strong likelihood that a dual relationship dilemma will be encountered" (Gonyea et al., 2014, p. 126).

Additionally, dual relationships are likely to naturally develop through time. Brownlee (1996) states that the longer a professional lives and works in a rural community, the more likely the individual will develop overlapping professional and personal relationships with others, and it will become impossible to avoid such interactions. Therefore, rehabilitation counselors are likely to encounter and have to manage dual relationships, and it may become impossible to avoid dual relationships as time goes on.

Finally, rehabilitation counselors who are from the same community in which they live and work are going to have to learn how to manage dual relationships. The counselor is likely to be acquainted with many clients or their family or friends, or clients will know of the counselor's family or be acquainted with the counselor's friends or neighbors. People may feel more comfortable seeking out a counselor from one's own community. A counselor who is local may have an easier time developing trust and building a therapeutic alliance with clients instead of someone who is not local.

Can Dual Relationships Be Beneficial?

While the CRCC does not condone dual relationships, it is recognized in the Code that sometimes nonprofessional interactions may be beneficial. The Code states that rehabilitation counselors avoid nonprofessional interactions with clients "except when such interactions are potentially beneficial to clients or former clients" (A.5.d). Potential interactions include "attending a formal ceremony (e.g., a wedding/commitment ceremony or graduation); purchasing a service provided by clients or former clients; hospital visits to ill family members; or mutual membership in professional associations, organizations, or communities" (A.5.d).

Research in rural ethics has suggested that some dual relationships may actually be beneficial (Dyck & Hardy, 2013; Malone & Dyck, 2011; Nelson, Pomerantz, Howard, & Bushy, 2007). According to Malone and Dyck (2011), at least low-risk boundary crossings "are often unavoidable in rural practice and can be considered a normal and healthy part of rural living" (p. 503). Behnke (2008) agrees, stating that "finding oneself in a multiple relationship is not necessarily a sign that one has engaged in unethical behavior. It may rather be a sign that one is fully engaged in the life of a community" (p. 62). In rural settings, counselors are likely to be expected to have to be active in the community or face being viewed as an outsider (Chipp et al., 2008). According to Chipp et al. (2008), being labeled as an outsider can have a serious negative effect on an already-resource-strapped community as community members may be less likely to seek that counselor's services, continuing to leave a gap in available services. Therefore, counselors are likely to lack anonymity or the ability to maintain nonoverlapping boundaries.

A careful balancing act occurs requiring the rehabilitation counselor to very carefully monitor the relationship or even the potential relationship. For example, Halverson and Brownlee (2010) in their study on ethical dilemmas social workers in remote areas of Canada face found that social workers did avoid dual relationships when possible. However, as they were often the only therapist serving a community, workers recognized that dual relationships were inevitable. In fact, surveyed workers reported that it was vital to develop strong ties to the community through active involvement in various organizations. Community involvement helped workers to network, to build valuable relationships with community leaders and elders, and to become a part of the "circle of trust" in the community (p. 255). Participants did report that it could be stressful to deal with dual relationships and had to be diligent that they discussed the likelihood of boundary crossings with all clients, included the definition of dual relationships and the likelihood in their informed consent forms, and developed and discussed techniques to manage dual relationships with colleagues and clients. Participants also made sure to fully assess a potential dual relationship before taking on a client as well as throughout the therapeutic process, asking the question "what is in the best interest of the client?"

Confidentiality and Privacy

Arguably, the most critical ethical issue rehabilitation counselors face working in rural areas involves confidentiality and privacy both for the counselor to protect client information and for the counselor himself or herself (Chipp et al., 2008; Shank et al., (2010). According to Arthur and Swanson (1993), confidentiality is "the ethical duty to fulfill a contract or promise to clients that the information revealed during therapy will be protected from unauthorized disclosure" (p. 91). According the Code (B.1.c), rehabilitation counselors are to respect the confidentiality of the people they serve: "Rehabilitation counselors do not share confidential information without consent from clients or without sound legal or ethical justification."

Privacy, however, is an "evolving legal concept that recognizes individuals' rights to choose the time, circumstances and extent to which they wish to share or withhold personal information" (Herlihy & Sheeley, 1987, p. 479). The Code (B.1.b) states "Rehabilitation counselors respect privacy rights of clients. Rehabilitation counselors solicit private information from clients only when it is beneficial to the counseling process."

While rehabilitation counselors must ensure the confidentiality of the clients served, they must also be mindful of cultural values. For example, the Code (B.1.a) states that rehabilitation counselors must maintain cultural competence in safeguarding the confidentiality of clients: "Rehabilitation counselors maintain beliefs, attitudes, knowledge, and skills regarding cultural meanings of confidentiality and privacy."

Client confidentiality and privacy can be difficult to maintain due to a variety of factors unique to small rural communities. These factors include *dual relationships between rehabilitation counselors*, *other providers*, *clients*, *families*, *and other community members*, *the high level of interconnectedness of rural communities*, *low population density*, and *high visibility of community members and counselors* (Malone & Dyck, 2011; Shank et al., 2010). In turn, these factors create for an interesting mix of issues around confidentiality and privacy that rehabilitation counselors are likely to face including reliance on informal supports, community gossip, confidentiality and collaborations, counselor's personal confidentiality, and indirect confidentiality issues. Let's look more in-depth at these issues.

Reliance on Informal Supports As rural people often rely on informal supports of family, friends, and local groups, along with the seemingly continuous budget cuts of community services, there is an even higher expectation that family, friends, and community groups are to provide the majority of support to loved ones with disabilities (Halverson & Brownlee, 2010). This shift in expectations and support puts more pressure on rehabilitation counselors and other providers to try to protect client confidentiality. Informal supports such as family and friends are going to naturally expect to be included in service and decision-making process.

Community Gossip Due to the low density of rural settings and high visibility of community members, counselors will likely hear much information about a client or a client's family outside of therapy. For example, a counselor's friends and family, such as spouse or significant other, children, or parents, may be acquainted with a client of the counselor, and the client's name and information may be brought up in regular conversation at meal time or get-togethers. This puts the rehabilitation counselor in a predicament, the counselor having to decide what to do with the information and whether or not this knowledge should be shared with a client (Shank et al., 2010).

Confidentiality and Collaborations There are also concerns with confidentiality and collaborations with others. Rehabilitation counselors who work with other providers are going to share client information. However, Malone and Dyck (2011) report that collaborating providers in rural areas are more likely to informally share information and "discuss cases openly without consent or expect this of all providers" (p. 211). Furthermore, rehabilitation counselors who do not engage in similar behavior of informally sharing confidential information or challenge informal oversharing "behavior of other professionals may alienate themselves and lose referral sources" (Malone & Dyck, 2011, p. 211).

Counselor Personal Confidentiality As rural communities are small and tight-knit, the community is going to hear information about a local rehabilitation counselor just as that counselor is likely to hear information about clients. This includes personal information about the counselor, the counselor's family, counselor or family activities, and family reputation whether it be good or bad. Counselor confidentiality can be difficult enough for rehabilitation counselors new to the community and prove near impossible for counselors from the area. Current and potential clients are likely to have family and friends who personally know the counselor or the counselor's family.

Indirect Confidentiality Issues Rehabilitation counselors are likely to face other issues with confidentiality that are indirectly related. Rural communities are fish bowls, with it being easy to look into the community and see what is going on. High visibility makes it easy for people to recognize people or their vehicles seen coming and going from the counselor's office, a name on client paperwork to other providers and agencies, or a private practice counselor depositing client checks at the bank (Malone & Dyck, 2011; Nelson et al., 2007). Also, people who use rehabilitation or other community resources are likely to know receptionists and other non-clinical staff (Coduti & Mannninen Luse, 2015; Nelson et al., 2007).

Due to such issues, rural rehabilitation counselors must take extra steps to protect client confidentiality and privacy. Counselors who do not take every precaution to protect confidentiality and even inadvertently break confidentiality can create serious harm for the individual as well as the community. Breaks in confidentiality and privacy result in the prevention of people from seeking services not only from a particular counselor or agency but other providers as well, increase stigma around seeking services, and can be a potential ethical violation of one's credential and/or licensure (Chipp et al., 2008; Schank et al., 2010). Rehabilitation counselors must be vigilant in ongoing discussions with clients regarding how much information is warranted to provide to well-intentioned others who do want to help or are actively involved in supporting the individual.

Role of Continuing Education and Supervision in Supporting Ethical Practice

An issue related to the ethical issues of both dual relationships and confidentiality includes the lack of focus of education and availability of supervision in rural areas. Counselor education programs, continued education, conferences, and even counselor literature do a poor job addressing rural issues and ethical dilemmas (Chipp et al., 2008; Halverson & Brownlee, 2010; Malone & Dyck, 2011; McAreavey, 2014; Shank et al., 2010). Education, training, and literature that do address dual relationships unfortunately usually recommend that counselors do not engage in such relationships, with little focus on how to effectively manage these relationships.

Another issue related to dual relationships and confidentiality is the lack of supervision that rural counselors often face (Malone & Dyck, 2011). For example, a rehabilitation counselor who works for a vocational rehabilitation agency or another organization providing vocational services to an area may likely have a supervisor; however, that supervisor may cover a large region with limited access to supervisees. As rehabilitation counselors may lack appropriate supervision, interdisciplinary collaborations with other area professionals and community leaders or elders will be highly important to ensure appropriate ethical behavior and competence (Malone & Dyck, 2011).

Implications of Technology to Manage Dual Relationships and Safeguard Confidentiality

The use of technology to provide therapeutic services such as telephone and videoconferencing and email has been found to be an effective means of delivering services (Dyck & Hardy, 2013; Halverson & Brownlee, 2010). The therapeutic alliance has also been found to be as equivalent in teleservices as in face-to-face services (Dyck & Hardy, 2013). Technological services can provide a highly effective way to address the needs of isolated and resource-poor communities, increasing service options for the people as well as referral and consultation options for local providers. Technological services can be conducted in the home or a local centralized location, reducing the need for traveling long distances as well as decrease travel barriers due to geography or climate. Telehealth and online services, particularly if conducted in the home, also address physical barriers to a building, making services potentially even more accessible, especially for those with severe disabilities. Home-based technological services can increase client comfort, decrease anxiety of being in an unfamiliar space, and facilitate trust, therapeutic alliance, and client disclosure (Halverson & Brownlee, 2010). Such services can also address social issues related to stigma, providing clients the privacy, confidentiality, and anonymity they desire. For rehabilitation counselors, the use of technology also addresses ethical dilemmas regarding dual relationships and confidentiality as well the lack of anonymity for the counselor himself or herself (Dyck & Hardy, 2013). A rehabilitation counselor could provide services to remote communities outside of one's own community, decreasing concerns of multiple relationships and trying to manage such relationships. A rehabilitation counselor who provides teleservices to a remote community can also more effectively safeguard confidentiality and privacy for clients. Finally, the use of teleservices can expand options for both the rehabilitation counselor and the client. Other providers who use technology can offer their services to a rural rehabilitation counselor and community or serve as a consultant to the rehabilitation counselor.

Limitations to the use of technology must be noted, however. The remoteness of a community and economy is the most significant barrier (Dyck & Hardy, 2013). Rural areas are more likely to experience poverty than more urban areas and lack funding and other resources to bring in telecommunication providers such as telephone and the Internet to create the necessary infrastructure. These factors affect the availability of technological services, Internet, and Internet speed which in turn affects quality of services such as videoconferencing. The expense of home computers, software, Internet service, and the time and energy potentially needed to learn how to use technology are additional factors which can create limitations to the use of service provision.

Rehabilitation counselors and other providers who utilize technological services such as videoconferencing and email must also consider the potential for hackers breaching technology and accessing counselor notes, email, calendars, and billing software that likely has highly confidential client information. Despite the best efforts of rehabilitation counselors to protect client information even with the use of secure Internet connections, encrypted email and case files, firewalls, malware, and antiviral software, there is no guarantee that a counselor's, or a client's, information will not be hacked.

Recommendations to Manage Dual Relationships, Confidentiality, and Privacy

This section of the chapter will provide guidelines to rehabilitation counselors on how to more effectively manage dual relationships and how to help protect confidentiality and privacy.

The Code provides little guidance for how counselors should respond to changes in the therapeutic relationships such as dual relationships. Standard A.5.f of the Code states that when there is a role change in the professional relationship, counselors must obtain informed consent from the client and discuss the right to stop counseling services if desired. Additionally, Standard Code (Standard A.5.d) states:

> In cases where nonprofessional interactions may be potentially beneficial to clients or former clients, rehabilitation counselors must document in case records, prior to interactions (when feasible), the rationale for such interactions, the potential benefits, and anticipated consequences for the clients or former clients and other involved parties. Such interactions are initiated with appropriate consent from clients and are time-limited.

The developers of the Code do recognize that it is impossible for the Code to address all combinations of ethical dilemmas. Therefore, the Preamble of the Code states "When faced with ethical dilemmas that are difficult to resolve, rehabilitation counselors are expected to engage in a carefully considered ethical decision-making process" (p. 2). Standard L of the Code provides guidance on resolving ethical issues as well as making it clear that rehabilitation counselors must ensure they are doing everything in their power to ensure they are handling all dilemmas in the most appropriate manner to ensure no harm. It is also made very clear that counselors have to take responsibilities for all of their actions and inactions to ensure no harm, and it is clear that there is no room for lack of knowledge. The Code (Standard L.1) states:

> Rehabilitation counselors are responsible for reading, understanding and following the Code, and seeking clarification of any standard that is not understood. Lack of knowledge of knowledge or misunderstanding of an ethical responsibility is not a defense against a charge of unethical conduct.

Standard L.2 of the Code does provide general guidelines for counselors to use to work through dilemmas. These guidelines include:

1. *Decision-Making Models and Skills*. Apply appropriate decision-making models.

2. *Addressing Unethical Behavior*. Address unethical behavior in oneself and other rehabilitation counselors, and adhere to the Code.
3. *Conflicts Between Ethics and Laws*. Obey both laws and statutes of the state counselors being practiced unless there is a conflict with the Code.
4. *Knowledge or Related Codes of Ethics*. Rehabilitation counselors have knowledge of other professional codes.
5. *Consultation*. Rehabilitation counselors are to consult with other knowledgeable professionals when faced with dilemmas.
6. *Organization Conflicts*. If an organization is in conflict with the Code, rehabilitation counselors are to make this known to supervisors and other officials of the organization and work to address the conflict.

Nelson et al. (2007, p. 138) also provide general guidance for how rural counselors can work through ethical dilemmas. In addition to general guidance, they also emphasize the importance that rural counselors bring awareness to the ethical dilemmas they face, as well as provide possible resolutions to such dilemmas:

- Increase awareness and understanding of issues on rural healthcare ethics as perceived by rural residents and healthcare professionals, including the contextual influence on ethical issues and how the issues are different from non-rural settings.
- Increase awareness and understanding of rural healthcare ethics decision-making, including how living and working in regionally diverse rural communities affect the response to ethical issues.
- Collaborate with rural healthcare professionals to draft guidelines for dealing with common, recurring ethical conflicts.
- Explore, assess, and propose models for "doing ethics" in small rural health facilities.
- Develop and implement ethics training curriculums and other educational resources for and with rural clinicians, administrators, and policy makers.
- Provide an ethics perspective to administrators and policy makers charged with allocating healthcare resources, supported by empirical data on potential urban-rural healthcare disparities.
- Foster a dialogue with the general healthcare ethics community regarding the unique nature of rural ethical issues.

Counselors may have to be creative and adapt a variety of strategies to ensure confidentiality and privacy of clients, some of which may conflict with the Code. Chipp et al. (2008), in their study on ethical dilemmas rural health providers face in New Mexico and Alaska, found that to help ensure confidentiality, providers:

- Work with community leaders to become competent in the local culture and develop culturally acceptable strategies that ensure confidentiality.
- Keep a private log of client information that is not part of official records.
- Expand regular office hours to include early, late, and weekend appointments so people do not have to explain or feel they must provide excuses to employers, coworkers, and others regarding their whereabouts.

Due to low density of rural communities and high visibility of residents, including counselors, other strategies to safeguard confidentiality include the use of community spaces such as a school, church, private room of a library, or a community hall, the use of local businesses after hours, or working with clients in the home (Coduti & Mannninen Luse, 2015).

Ethics researchers have provided more guidance on how to approach potential dual relationships. For example, Barnett, Behnke, Rosenthal, and Koocher (2007) (as cited in Shank et al., 2010, p. 504) propose six questions counselors should ask themselves when working through ethical dilemmas. These questions would be appropriate for rural rehabilitation counselors to think through when faced with the possibility of a boundary crossing and to ensure they do not harm clients or the community they serve:

- “Will doing this be helpful to my client?”
- “Will this action likely harm anyone?”
- “To whom do I owe an obligation or allegiance in this situation?”
- “Will this action likely promote dependence on me by my client?”
- “Are my actions consistent with how other providers treat their clients?”
- “Have I allowed my judgment to become impaired as a result of inadequate attention to my own care of needs?”

Dual relationships with former clients may be particularly difficult to avoid and be even more problematic than dual relationships with current clients. Anderson and Kitchener (1998, p. 96) provide two questions for counselors to use as the beginning framework to process possibilities when deciding whether or not to enter into a dual relationship with a former client:

- “Is a post-therapy relationship avoidable, and if it is, why am I considering entering it?”
- “One year from now, will I be satisfied with my decision?”

Schank et al. (2010, p. 504) provide four steps for counselors to take into consideration when dealing with ethical dilemmas such as dual relationships:

- *Obtain Informed Consent*
  - Be very clear with clients about confidentiality and limits, how records are kept, services, incidental contact, overlapping relationships and how they should be handled, and consultation with other providers.
- *Document Thoroughly*
  - Must document thoroughly overlapping relationships and reason for entering into the relationship. Must document consultation with other professionals around overlapping relationships and other ethical issues and discussion with clients.
- *Set Clear Boundaries and Expectations*
  - Discuss with clients professional and client expectations in the therapeutic relationship and clarify obligations and limitations, especially where it may be difficult to control out-of-office contact. Need to consider best and worst possible outcomes of relationships and need to address ways to prevent harm. Must self-monitor continuously.
- *Pay Attention to Issues of Confidentiality*
  - It can be tough to remember where information was gathered from (in or outside of sessions with a client). Word travels quickly in small communities, and rumors can be prevalent.

Instructional Features

Discussion Box 6.1

Joe is the only vocational rehabilitation counselor covering an entire county. He provides vocational services to Juan, whose parents, Mrs. and Mrs. Hernandez, are very active in the community and are major monetary supporters of local youth programs. Juan’s mother is also the town’s mayor. There has been much community gossip that the Hernandez’s are having financial and marital difficulties which could significantly impact the community. One youth program that they are the major contributor of is a program in which Joe is a board member. The previous week when the board met, there was discussion of these rumors and what it could mean to the program if the Hernandez’s could no longer support it. One of the board members is a teacher in the local high school and knows that Joe and Juan work together. She pulls Joe aside after the meeting and asks him if he knows what is going on or if he can find out. Joe has noticed during his last few sessions with Juan that the youth appears sad, withdrawn, and having difficulty completing employment search activities Joe assigns him. During their next meeting, Joe asks Juan if everything is alright.

Questions

1. Discuss the differences between confidentiality and privacy related to this scenario.
2. When would Joe violate Juan's privacy?
3. When would Joe violate Juan's confidentiality?
4. Discuss Joe's obligation to the youth program and the board, if any, regarding information he learns during his meeting with Juan.
5. What are the appropriate steps Joe should take to ensure Juan's confidentiality and privacy?

Research Box 6.1

See Malone and Dyck (2011).

Objective: Using the Canadian Code of Ethics for Psychologists (CPA), the researchers examined ethical dilemmas rural and remote providers faced and their ethical decision-making process.

Methods: This was a qualitative examination of ethical dilemmas the two authors have faced as rural and remote psychologists. The authors discuss several real case scenarios they have experienced using the CPA which provides real-world, practical solutions that other providers can implement.

Results: Providers can face many ethical situations working in rural and remote areas including dual relationships and confidentiality, pressure from colleagues to divulge client confidential information, and competence and self-awareness of one's limitations.

The authors discuss the importance of locating colleagues and supervisors whom the provider can trust to work through ethical dilemmas with. Due to limited service providers in rural and remote communities, providers often have to develop a generalist approach to be able to see clients with a wide variety of needs. The authors do discuss both the pros and cons of developing a generalist practice. Providers who practice as generalists are better able to serve a diverse population. However, there are concerns regarding competence, scope of practice, and training. To help counter ethical concerns, providers must develop relationships and collaborate with colleagues throughout the local and regional healthcare systems. Well-developed collaborations with other providers are highly useful to meet the often complex medical, personal, and environmental needs of community members.

Conclusion:

It is important for rural providers to develop relationships with colleagues or supervisors they can rely on to assist in processing and solving ethical dilemmas. Rural providers must also locate appropriate resources such as training, literature, and research that focus specifically on rural ethical dilemmas. The authors conclude with highlighting the rewards of working in rural and remote communities and possible benefits of engaging in dual relationships and having close ties with the community.

Questions:

1. Compare the CPA to the CRCC Code of Ethics, focusing on dual relationships, confidentiality, competence, interdisciplinary teamwork, training, and supervision.
2. What does each Code discuss regarding these topics?
3. Does one Code provide more thorough guidelines for rural counselors to use? Explain.
4. How can you implement suggestions from this article into your own work as a counselor?
5. How could you implement suggestions from the CPA into your own work in an ethical manner?

Decision-Making Models

Due to the number of different helping professions and the various populations that are served, there are a variety of different ethical decision-making models that may be helpful. "These models cover a variety of foci, including multiculturalism, collaboration, counselor education, and counselor settings, such as schools and community agencies" (Heller Levitt, Farry, & Mazzarella, 2015, p. 84). While having a variety of models to choose from, and no two are like, can be very helpful, this can also become overwhelming to counselors when looking for a model that best serves one's needs.

Herlihy and Corey's Decision-Making Model

Herlihy and Corey (2015) provide a general guide for professionals to use when faced with difficult ethical dilemmas. They provide the following steps that can be used when a rehabilitation counselor is faced with a potential dual relationship or issues regarding confidentiality.

Identify the problem: Recognize a problem that exists, and determine the type of problem it is: ethical, legal, professional, clinical, or a combination. Then, gather as much information as possible. Make sure to document thoroughly throughout the process.

Identify and examine relevant codes and principles: Consult the appropriate professional ethical code(s) and principles. Make sure to completely understand the code's standards and principles as well as possible implications. Make sure to evaluate if one or more standards and principles have priority over others.

Consult with others: It is important to discuss problems with colleagues and supervisors. Consulting with others can be very helpful as they may have more expertise in an area, had similar experiences, and can offer another perspective. Make sure to document throughout the consultation process.

Check your emotions: Throughout this whole decision-making process, it is important for the counselor to be self-aware of one's emotions. The counselor will need to "check to see whether you are being influenced by feelings such as fear, self-doubt, frustration, disappointment, or an overwhelming sense of responsibility" (Herlihy & Corey, 2015, p. 21). It can also be very beneficial to talk about and process emotions with colleagues and supervisors.

Involve the client: Counselors must make sure they are following the general principles, particularly autonomy in the decision-making process, and the ethical standards such as informed consent. Clients should be involved in the problem-solving process; it is their case after all by including the client in the process they are being empowered to make the best decision for himself or herself.

Cultural considerations: Make sure to be fully aware of what role one's personal cultural and worldviews may have in the problem and decision-making process. Counselors must also consider the client's culture and worldview and ensure the problem is a good fit for the individual.

Problem-solve: The counselor can start to generate possible solutions. It is wise to develop many possible solutions.

Consider all consequences: As all possible solutions are generated, it can be highly beneficial to either rank them or develop a pro/con list to help both the counselor and client understand what all potential consequences may entail. Eliminate solutions that do not have an effective or favorable outcome or may cause further problems. Again, it is important to include the client in this process throughout.

Evaluate selected courses of action: Now that possible solutions have been whittled down to a few options, it is important to compare them to the counselor's general principles and standards. Standler (as cited in Herlihy & Corey, 2015) recommends testing options. This test includes the test of justice (assess personal sense of fairness in this option), the test of publicity (would the counselor want this solution and his/her behavior broadcasted on the news?), and the test of universality (would the counselor recommend this same solution to another helper?). If the counselor is satisfied to each answer, then he or she can move on the final step. If not, then test another possible solution.

Implementation: Now, the counselor and client can carry out the decided course of action. Once the solution is implemented, it is important to follow up to assess its effectiveness and consequences.

Tarvydas Integrative Model for Ethical Behavior

Tarvydas (2004) also provides a model for rehabilitation counselors to use when faced with ethical dilemmas. This model contains four stages:

Themes or Attitudes in the Integrative Model
- Maintain an attitude of *reflection*.
- Address *balance* between issues and parties to the ethical dilemma.
- Pay close attention to the *context*(s) of the situation.
- Utilize a process of *collaboration* with all rightful parties to the situation.

Stage I. Interpreting the Situation Through Awareness and Fact-Finding
- *Component 1.* Enhance sensitivity and awareness.
- *Component 2.* Reflect, to determine whether dilemma or issue is involved.
- *Component 3.* Determine the major stakeholders and their ethical claims in the situation.
- *Component 4.* Engage in the fact-finding process.

Stage II. Formulating an Ethical Decision
- *Component 1.* Review the problem or dilemma.
- *Component 2.* Determine what ethical codes, laws, ethical principles, and institutional policies and procedures exist that apply to the dilemma.
- *Component 3.* Generate possible and probable courses of action.
- *Component 4.* Consider potential positive and negative consequences for each course of action.
- *Component 5.* Select the best ethical course of action.

Stage III. Selecting an Action by Weighing Competing, Nonmoral Values
- *Component 1.* Engage in reflective recognition and analysis of personal competing values.
- *Component 2.* Consider the contextual influences on values selection at the collegial, team, institutional, and societal levels.

Stage IV. Planning and Executing the Selected Course of Action
- *Component 1.* Figure out a reasonable sequence of concrete actions to be taken.
- *Component 2.* Anticipate and work out personal and contextual barriers to effective execution of the plan of action and effective countermeasures for them.
- *Component 3.* Carry out and evaluate the course of action as planned.

Future Implications that Potentially Will Influence Service Delivery and Approaches

Due to geographical, demographical, and cultural factors of rural and small town settings, rehabilitation counselors who serve these communities are likely to make adaptations to services that are different compared to their urban counterparts, particularly when it comes to managing dual relationships and safeguarding confidentiality. Therefore, there are implications for policy makers and funding agencies, educators, and researchers to ensure rehabilitation counselors are able to provide high-quality, ethical services in rural settings.

Policy makers and funding agencies must recognize that rural communities face many barriers to access appropriate care. Rural communities face geographical, climatic, and infrastructural barriers; limited community services; and limited employment opportunities and jobs that provide adequate health insurance. These factors limit options for community members and place much stress on available services and providers. Rehabilitation counselors working in resource-poor communities are more likely to work with people they have social connections with. While dual relationships can be beneficial as research has indicated, rural counselors have indicated that managing such relationships can be stressful, often not ideal, and if not managed correctly can have negative consequences for clients, counselors, and the community. The likelihood of having to engage in dual relationships creates issues in assuring client and even counselor confidentiality and privacy. And again, as with dual relationships, breaks in confidentiality have very serious consequences for all involved including the community. Rural communities and counselors would benefit from legislation and policies strategically geared toward their unique needs. Furthermore, rural communities and agencies require funding to bolster service options and alleviate stress from the few available service providers and decrease risks for dual relationships and confidentiality and potential consequences. Additionally, counselors require funding to seek out appropriate training and supervision to be able to effectively manage dual relationships and confidentiality. Counselors and agencies would also benefit from funding to develop training services for other rural providers. Funding geared toward technology and technological infrastructure would also help to increase service options to rural communities and increase collaboration, training, and referral resources for counselors. However, technology is not the only answer either. Policy makers, funding agencies, and local community providers must come together to adequately understand the many issues dealt with in rural settings and develop specific interventions that will be most effective.

Education programs, continuing education training and research, place little emphasis on the unique needs of rural settings, with most of educational programming and research maintaining an "urban-centric" viewpoint (Coduti & Mannninen Luse, 2015; Malone & Dyck, 2011). Research has repeatedly indicated that rural counselors face challenges surrounding dual relationships and confidentiality that are both "quantitatively and qualitatively different than those faced by urban providers" (Chipp et al., 2008, p. 545). Unfortunately, rural providers often rely on anecdotal strategies to manage dual relationships and assure confidentiality (Schank et al., 2010). Researchers must examine counselor ethical decision-making processes and resulting implemented strategies to evaluate benefits and risks of dual relationships and management. Rehabilitation counselors, like any other human service and healthcare providers, are most often trained to avoid dual relationships. Additionally, while rehabilitation education, training, and research is well informed regarding the importance of confidentiality and consequences of breaking it, there is little investigation of how to safeguard confidentiality in rural settings with low population density and high visibility. Rural counselors would be well served by the provision of well-examined strategies to manage dual relationships as well as strategies to recognize when and when not to enter into a dual relationship and effective strategies to protect confidentiality. Through empirical well-informed education and training geared specifically toward rural ethical issues, rehabilitation counselors could provide high-quality, ethical, and culturally sensitive services to their communities.

Summary

It is hoped that this chapter will help students to recognize that rural and small town settings are unique and that working in these communities will provide not only many challenges but also many opportunities. Rural and small town communities are diverse, vibrant communities that deserve respect to be provided a range of empirically sound and ethical services that meet their needs. This chapter sought to address the issues rural and small town settings face along with cultural values that create for unique ethical dilemmas for rehabilitation counselors particularly regarding relationship dynamics.

The Code, while designed to provide broad guidelines to assist in multiple settings, may be too ambiguous and not culturally sensitive for rural and small town communities. Furthermore, there is a significant gap in education, training, supervision, and research to provide rural-focused strategies to assist counselors to be able to effectively problem-solve and manage ethical dilemmas. Rural counselors are likely to have to deal with dual relationships and must be able to effectively manage these precarious relationships. Training counselors to avoid such relationships is simply not realistic, nor may it be ethical. Without the provision of empirically validated training and supervision, rural counselors have been left on their own to develop and implement anecdotal strategies to manage dual relationships and confidentiality. Furthermore, rural and small town communities are often tight-knit; rely on informal supports such as family, friends, and informal groups; and are resource-poor. Therefore, it would be unethical to ignore the potential necessity of counselors to have to engage in dual relationships.

Working in a rural community and engaging in some types of dual relationships with clients can be a positive and beneficial experience. Counselors who take the time to become engaged in a rural or small town setting will recognize that these are rich and highly diverse communities, with self-reliant, highly resourceful, very caring, and connected community members. In-depth community involvement allows counselors to be highly visible and become a trusted community member in which people feel comfortable seeking services from, recognize and bring awareness to community needs, and dispel stigma attached to disability and service seeking. Counselors can more fully engage the community as a whole and individuals in conversations about how to tackle community concerns and develop strategic services that are culturally appropriate to fit the community's needs. Dual relationships can also be beneficial to allow the counselor to work more closely with individual clients to develop holistic, really in-depth, highly effective services that include a variety of informal supports from family members to friends, to community groups, and to the involvement of local businesses. Counselors working in resource-strapped communities, who can ethically manage boundary crossings, will have informal resources and supports, such as community leaders and elders, whom they can turn to for their own guidance as well as to assist in service provision.

Case Study

Miguel is a 15-year-old young man who is a freshman in high school. He has Duchenne muscular dystrophy. Miguel attends his IEP meeting and recognizes you, the only vocational rehabilitation counselor in the county, as a friend of his parents. You ask Miguel to meet you for a few minutes after the meeting to discuss a little more in-depth what VR services include and some of Miguel's personal and career goals. Miguel appears embarrassed talking to you. When you ask him what questions he has, he asks if you are going to tell his parents everything you discuss. Explain dual relationships, confidentiality, and privacy in terms a 15-year-old young man would understand. Discuss the steps you can take to ensure Miguel's confidentiality and privacy.

Resources

National Rural Health Association: http://www.ruralhealthweb.org/Research and Training Center on Disability in Rural Communities: http://rtc.ruralinstitute.umt.edu/employment-vocational-rehabilitation/

Rural Health Information Hub: https://www.ruralhealthinfo.org

Rural Health Research Gateway: https://www.ruralhealthresearch.org/centers

Rural Policy Research Institute: http://www.rupri.org/

US Department of Health & Human Services: Federal Office of Rural Health Policy: http://www.hrsa.gov/ruralhealth/

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Learning Exercises

Self-Check Questions

1. Discuss the role of culture in dual relationships, confidentiality, and privacy.
2. Discuss why it is important for rehabilitation counselors who work in suburban and urban areas to learn about and understand the culture and needs of rural and small town communities and ethical dilemmas rural counselors face.
3. You are a rehabilitation counselor in a remote rural community. You are asked to attend as a guest in the board meeting of a local organization you are very interested in. As you walk into the first meeting, you realize the board president is the parent of a teenager you work with in the high school. The teen has recently disclosed negative personal information about this parent to you. What steps regarding confidentiality and privacy do you take in handling this situation?
4. Max is a rehabilitation counselor who has his own private practice. He lives and works in a small rural town. Max's car breaks down, and he has it towed to the service garage owned by a client's parent, which is one of the two garages in the community. The estimate on repairs is very expensive. As a proprietor, the garage owner pays for his own insurance. His insurance only covers six counseling sessions for his child, which will occur after Max's next session with the client. The family has agreed that they would like Max to continue working with the child and have begun discussing payment options. At the garage, Max and the garage owner agree to the arrangement in which Max will provide services pro bono to the owner's child in exchange for repairing his car.
   - Discuss whether or not Max should make this arrangement with the garage owner. Explain your answer.
   - What are the positive and negative implications of this proposal?
   - What kind of dual relationship would this be? Explain why.
   - If you believe this arrangement is alright, what steps must Max take to ensure it is ethical and does not harm his client or the family?
5. Mary is a rehabilitation counselor who grew up in the tight-knit farming community she works. She has covered the same large region for several years and will frequently meet clients in their homes. She has several

clients in which she has had long-term therapeutic relationships with. Clients will frequently say hello to Mary in the community. During home visits, clients usually offer Mary coffee and food and want to inquire about Mary's family as they frequently know each other's families.

- What are the implications of the client and Mary's behavior in these relationships?
- What steps should Mary take to ensure boundaries?
- What steps should Mary take to protect both her and client confidentiality and privacy?

Field-Based Experiential Assignments

1. Interview a vocational rehabilitation counselor who works in a rural setting. Discuss with the counselor:
   - How the counselor manages dual relationship dilemmas with clients.
   - How the counselor manages confidentiality and privacy dilemmas with clients in a culturally appropriate manner.
   - What strategies does the counselor use to solve ethical dilemmas?
   - What ethical decision-making models does the counselor use to solve ethical dilemmas?
2. Develop a case study that includes ethical dilemmas around dual relationships and confidentiality. Have classmates use one of the ethical decision-making models discussed in this chapter to develop ethical strategies to work through the dilemmas.
3. You are part of a group of rural rehabilitation counselors visiting your state capitol to speak with your local members of congress and then visiting Washington DC to speak with your state members of congress. Outline and discuss (and explain why) three major points you would want to discuss that have implications for dual relationships, confidentiality, and privacy.

Multiple-Choice Questions

1. True or False. Mary is a rehabilitation counselor who covers a large region. While the agency she works for is centrally located in town, most of her clients live several miles outside of town. Transportation, healthcare issues, and child care often create challenges for clients to be able to see Mary in the office. Therefore, Mary will frequently meet clients either in their homes. This would be an example of a boundary crossing.
2. True or False. Greg is a rehabilitation counselor who lives in the same community where he works. While grocery shopping, Greg runs into a client, Alex, and his parents. Alex and his parents stop and say hello to Greg. This would be an example of a boundary violation.
3. True or False. Informal overlapping relationships between the counselor and client are called dual relationships.
4. Strategies to manage dual relationships do not include which of the following:
   (a) Discuss the likelihood of boundary crossings with every client.
   (b) Define dual relationships, and discuss likelihood of such relationships in the counselor's informed consent.
   (c) Discuss strategies with colleagues to manage dual relationships
   (d) Counselors are to avoid all dual relationships.*
5. Which of the following is an appropriate question that a counselor can use to determine whether or not to enter into a dual relationship with a client?
   (a) "Will doing this be helpful to my client?"
   (b) "Will this action likely harm anyone?"
   (c) "Are my actions consistent with how other providers treat their clients?"
   (d) All of the above are questions that can be used to determine whether a decision is ethical.*

6. Which is not an example of a low-risk boundary crossing?
    - (a) Conducting a home visit with a client
    - (b) Meeting clients in a private room at the local community hall
    - (c) Working with a teenage client who is friends with your child*
    - (d) Running into a client at a local restaurant
7. According to Schank et al. (2010), steps counselors should take to effectively manage dual relationships include which of the following:
    - (a) Document all dual relationships carefully, including the reason for entering into the relationship.
    - (b) Discuss and set clear boundaries and expectations with all clients.
    - (c) Be diligent to issues regarding confidentiality in a dual relationship.
    - (d) All of the above are suggested strategies to manage dual relationships.*
8. Cultural factors that can hinder a counselor's ability to protect client confidentiality include which of the following:
    - (a) Rural residents are likely to rely on informal supports such as family and friends.
    - (b) Low population density and high visibility create for likelihood of gossip.
    - (c) Low population density and high visibility create for community members indirectly learning about confidential information of a counselor's client.
    - (d) All of the above are cultural factors that can hinder confidentiality.*
9. Strategies to protect client confidentiality include which of the following?
    - (a) Become competent in the culture of the local community to understand individual and community expectations regarding who is likely to be an informal support, who can know certain information, and what information is shared.
    - (b) Expand office hours to accommodate client preferences.
    - (c) Locate a private space in a central community location such as a church or community building.
    - (d) All may be appropriate ways to help ensure client confidentiality.*
10. A rehabilitation counselor's ethical duty to protect client information discussed during therapy is__________.
    - (a) Privacy
    - (b) Confidentiality
    - (c) Dual relationship
    - (d) Boundary violation

Key

1 – T
2 – F
3 – T
4 – D
5 – D
6 – C
7 – D
8 – D
9 – D
10 – B

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Resilience and Strengths of Rural Communities

7

Allison R. Fleming, Noel A. Ysasi, Debra A. Harley,
and Malachy L. Bishop

Overview

The word resilience has a historical association with recovery from natural disasters and with very precise meanings in disciplines such as engineering and ecology. However, the word resilience has traveled an evolutionary path from such precisions to a more inclusive way to describe a characteristic of individuals, households, communities, or regions (Dabson, Heflin, & Miller, 2012). Wilbanks (2008) defined a resilient community or region to possess the characteristics to (a) anticipate threats, opportunities, and potential for surprises, (b) reduce the impact of these threats, (c) respond appropriately when these threats materialize, and (d) recover afterward. Resiliency of rural residents may best be summarized based on their trajectory. Over time, rural residents have demonstrated not only resilience but resistance and recovery, three of the elements identified by Norris, Stevens, Pfefferbaum, Wyche, and Pfefferbaum (2008) as trajectory, with the fourth being long-term dysfunction. In addition to individual characteristics, traditional beliefs, and practices, environmental and geographical influences in rural communities tend to increase personal resistance.

Often, rural communities are viewed as vulnerable because of location; however, it is important to recognize that vulnerability is not a static state nor is it an attribute of an individual or system/community. According to Rance, Funfgeld, and Brown (2015), vulnerability "is characterize by a host of complex social and economic factors, often associated with entitlements and access of individuals or groups to resources relative to the geographic and institutional context in which these individuals or groups live" (p. 10). The tools that individuals possess to deal with challenges, change, or loss are what define their level of resilience and strengths. In other words, resilience does not make life easier or remove obstacles for individuals; rather, it provides psychological strength to understand that challenges are inevitable and that it is necessary to work through them. In any discussion of resilience, it is important for the reader to remember that resilience often exists within the context of risk.

Rural people and communities have demonstrated resilience in light of institutional and social changes that have occurred since the

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A.R. Fleming (✉)
Rehabilitation and Human Services, Pennsylvania State University, University Park, PA, USA
e-mail: apf508@psu.edu

N.A. Ysasi
College of Health and Human Services, Rehabilitation Services and Rehabilitation Counseling,
Northern Illinois University, DeKalb, IL, USA

D.A. Harley • M.L. Bishop
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA

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mid-twentieth century and have fundamentally transformed rural life (Brown & Schafft, 2011). While there are multiple reasons for rural resilience, overwhelmingly and universally the literature consistently attributes rural resilience and strengths to social capital (the quality of relationships between members of the community), value of kinship, and pride. This chapter will present information on the sustained ability of rural, frontier, and territory communities to respond, withstand, and recover from adversities as a measure of strengths of rural residents.

Learning Objectives
Upon completion of this chapter, the reader should be able to:

1. Define resilience.
2. Identify the characteristics of resilience and strengths in rural residents and communities.
3. Explain community capacity.
4. Define social capital, and explain its relevance for resilient communities.
5. Identify areas for possible community advocacy to increase resilience.
6. Understand the advantages and disadvantages of the social conditions of resilience.

Introduction

Rural communities have often been viewed as "behind" or less progressive than urban centers (Thomas, Lowe, Fulkerson, & Smith, 2011). This point of view is driven by a concept called urbanormativity, or the view that urban space in the USA is the norm, and rural communities are abnormal (Thomas et al., 2011). Urbanormativity contributes to the marginalization of rural spaces and communities and does not acknowledge the value and contribution of rural parts of the USA. Common thinking is that rural communities rely on urban centers for innovation and sustainability; however, amassed evidence suggests just the opposite. In fact, urban centers rely on rural communities for food, materials, and natural resources. Historically, rural areas have been the setting for many social changes in the USA; several groups seeking freedom from oversight and influence moved to rural areas to create their own society based on their own beliefs (Thomas et al., 2011). This tradition creates the backdrop for many rural communities today: resilient, self-sufficient, and independent. The following sections will provide an overview of the definition of community, the concept of community resilience, and community capacity.

Communities are traditionally defined as, "people, resources, organizations, structures, and systems in a close geographic proximity" (Pfefferbaum et al., 2013, p. 251), recognizing some imposed physical boundaries are inaccurate reflections of a community. In a rural context, a community may be thought of as a county or area that all utilize central community resources such as schools, churches, mail routes, or law enforcement. Rural communities are often subject to hardships due to economic circumstances, natural disasters, and shifts in demographic makeup of residents over time. Despite these challenges, many display an incredible amount of resilience and continue to thrive despite difficulties. Often, residents are credited with adapting and changing with the times, while "outsiders" often have difficulties understanding how this is accomplished.

Community resilience as a concept has gained attention in the public health arena as critical to the welfare of citizens, particularly in support of the US Department of Health and Human Services National Health Security Strategy to prepare for threats due to disease, natural disasters, and terrorist attacks (US Department of Health and Human Services, 2009). Community resilience is sometimes described as a goal, other times as a mechanism for ensuring preparedness for emergency situations and threats (Pfefferbaum & Klomp, 2013). Resilience can describe individuals or communities and can be simply defined as "the process of successfully adapting to, and recovering from, adversity" (Pfefferbaum & Klomp). Many counties, towns, and communities are subject to difficult circumstances or events, and residents who are able to return to pre-event levels of quality of life are considered to be more resilient (Besser, 2013). Based on this definition, resilience can be conceptualized as a dynamic process that is observed over time as the community identifies, responds to, and monitors potential threats. Resilience itself does not reflect the absence of hardship, rather describes continued progress despite adversity. Resilience at the community level is a phenomenon apart from the resilience of the residents, although the two are not completely mutually exclusive. Pfefferbaum and Klomp (2013) explain this important distinction by building on the familiar adage, “the whole is greater than the sum of its parts.” The collection of resilient community members joining their efforts is the backbone of community strength. However, a resilient community does not guarantee resilience in all residents and does not necessarily strengthen or impact individual community members. This chapter will be a discussion of community capacity, resilience, values, and strengths of rural communities, including examples of community programs that demonstrate the impact of community service delivery on residents.

Defining Community Capacity

Many disciplines, including community health, economics, sociology, and public policy, are the home to research, literature, and general discourse on the topic of community capacity. Often, economic indicators such as poverty, employment, and even population growth are the focus of this work. Other scholarly endeavors highlight the importance of social and organizational gains such as education, community activity and participation, and satisfaction. Beckley, Martz, Nadeau, Wall, and Reimer (2008) propose that community capacity is better understood as a multidimensional concept, including structural and relational components and community assets. Structural components are most easily understood as the way a community is situated, including availability of natural resources, connections with or isolation from other geographic areas, local power structure, and/or political and governmental characteristics. Relational components consist of community leadership, cohesion, shared values, and traditions of community members. Community assets are commonly considered to be infrastructure, liquid financial assets, or entrepreneurial social structure. Additionally, there are a wide variety of outcomes that may indicate strong or weak community capacity outside of those traditionally considered. Beckley et al. (2008) proposed a multidimensional definition of community capacity, with four facets: “(a) capital, assets, or resources; (b) catalysts; (c) mobilization of those resources through social organization and relationships; and (d) end results or outcomes” (p. 60).

Alternatively, Pfefferbaum and colleagues (as cited in Pfefferbaum et al., 2013) proposed four interrelated domains of community capacity that both “describe and help create” the capacity for community resilience: (1) connection and caring, (2) resources, (3) transformative potential, and (4) disaster management. Connection and caring describe the relatedness, shared values, and community participation of members. Communities that foster involvement and engagement of residents in diverse groups and experiences (e.g., civic, social, etc.) increase the shared sense of belonging and investment in the community. For example, festivals and fairs can foster relationships, community pride, and belonging (Kulig, Edge, & Joyce, 2008). Community social networks can also be a source of hope and support during crises. Resources have traditionally been characterized as a wide variety of resource types: financial, natural, physical, human, and social. Above the existence of resources, Pfefferbaum and colleagues emphasize that the way that communities invest in and allocate resources is critical to resilience in the face of disruption or challenge. The structure and organization of a community, for example, ensure members can respond effectively and quickly in times of crisis. The transformative potential of a community addresses the members’ capacity to identify and frame their collective experiences, assess and consider strengths and weaknesses, examine past initiatives, and make plans and decisions for the community’s future. Disaster management includes activities set up in advance to mitigate risk, to be prepared for crises by way of developing and planning response, and speed recovery from unforeseen or unpreventable events. This process requires assessment of possible and likely threats, areas of vulnerability, resource needs, and determining appropriate actions. This is an ongoing process, where both short-term needs and long-term plans for recovery are included.

Sustainability, vulnerability, resiliency, and adaptability are terms frequently cited within the literature to describe how communities adjust and overcome adversity. These concepts have been the emphasis of resource and land management and how individuals and communities respond to natural disasters and/or extreme weather conditions (Harrington, 2005). Rural communities in the great plains and high plains of Kansas, for example, are known to experience severe weather conditions including drought, tornadoes, hail, and freezing temperatures and ice/snow, often affecting a region highly dependent on agriculture (Cross, 2001; Cutter, Boruff, & Shirley, 2003). In the 1930s, the drought and dust bowl (well-known natural disaster) affected the region through the loss of rich farming soil associated to wind and water erosion. Moreover, depleting groundwater, floods, and tornadoes/hail/severe storms remained persistently problematic (Borchert, 1971; Harrington, 2005). Yet, despite these conditions, communities in rural Kansas continue to thrive. Subsequently, Kansas has made vast efforts to respond to these environmental challenges experienced within their rural communities. Mitigating factors for overcoming these socioeconomic conditions have been adaptability and resiliency among farmers for adopting new methods of farming, while state and federal involvement through research programs have provided additional support for locals. Hence, the implementation of soil conservation practices through a Western Weather Modification Program is designed to increase rainfall and reduce hail damage (Nellis et al., 1997). Interestingly, no signs of increased rainfall through the program came about; however, overall hail damage decreased by 49%, damage to crops decreased by 27%, and provided an estimated cost benefit of $60,000,000 for the years 1979–1993 within six rural communities. The overall significance of this program resulted toward further adjustments to counter other environmental conditions (i.e., droughts, floods, etc.) through agriculture diversification (i.e., conversion to dryland farming), adopting efficient technologies, espousing crop rotations, increased irrigation, and water conservation programs (Eklund, Jawa, & Rajala, 1999; Harrington, 2005). Additional methods for adjusting to the environmental conditions are necessary for long-term sustainability (Harrington, 2005).

Though, not every country responds to the need or challenges typically seen in our example of Kansas. In 2003, the World Economic and Social Survey was released which focused on sustainable development, a fundamental concern in developing countries facing challenges with economic, social, and environmental issues (United Nations, Department of Economic and Social Affairs [UNDESA], 2013). Their report offers insight not only to the challenges frequently encountered in rural populated areas but also solutions to overcome global challenges through a joint course of action among governments. The United Nations addressed the need for investing in rural infrastructures as determinant for increasing food production and sustaining natural resource management.

For instance, in agriculturally based countries such as sub-Saharan Africa, transportation accounts for 50–60% of total marketing costs, yet poor road conditions continue to remain; investing in basic infrastructure, such as roads, potable water, and supplying electricity, can reduce marketing costs and vitalize local economies through increased production. By addressing these long-term constraints, opportunities for expansion will be possible and attractive among private investors (UNDESA, 2013). Case in point, Uganda generates a 23% GDP for agriculture but has significant deficits in physical infrastructure. However, their government has recently invested toward improving physical infrastructure (primarily for irrigation projects) to increase productivity and enhance food production capacity. Researchers hypothesize Uganda's annual productivity growth rate over the period 2016–2030 will increase from 2.4% to 3.7%, and agricultural output will increase 1.5% per year (UNDESA, 2013). These investments further support the need for commitment from the public as they will ultimately contribute to productivity gains.

Additional challenges and/or concerns among these communities included the need for food security and income among the rural poor. Not only will increasing agricultural productivity improve economic conditions but also facilitate increased food availability while simultaneously generating income. Investing in rural communities is critical for an integrated approach to sustainability and decreasing poverty. Further, UNDESA (2013) recommends a rural development strategy through rural infrastructure investments to improve working alliances between rural and urban communities and implementing wider and inclusive access to public services to reduce rural/urban inequalities, disaster risk, and food insecurity.

Assessing Community Strengths

Effective and resilient communities build on their strengths, adjust for weakness, and recognized environmental and economic realities (United State Department of Agriculture Economic Research Service, 2012). Community members may wish to employ assessments to help identify and guide their approach. A person serving in a leadership or evaluator role in a community assessment exercise is by the nature of the task, performing a political activity. Careful attention to empowering community residents and valuing their perspectives as a form of "truth" is critical to success (Tice, 2005). Put simply, "the strengths assessment requires an account of what people know and what they can do, however inchoate that may seem. It requires constructing a roster of resources existing within and around the community" (Tice, 2005, p. 100).

Assessing communities for capacity allows for recognition of both community strengths as well as areas of weakness. Those in a community development capacity who are aware of community capacities or strengths, as well as gaps or weaknesses, can ensure that necessary supports are in place prior to initiating any programs or initiatives (Goodman et al., 1998). One method of assessing community strengths that have gained particular attention in the field of social work is "community mapping" (Pitzer & Streeter, 2015). The concept of "mapping" is often thought of within the concept of geographic space but can also be extended to include abstract concepts such as social capital or assets. Mapping community strengths can enhance the community members' and outside helpers' understanding of assets and enhance the self-efficacy of the community, potentially boosting engagement in further asset development (Pitzer & Streeter, 2015). As with any evaluation effort, during an asset mapping exercise, it is important to gather data or input from as many sources as possible. This means tapping the knowledge and expertise of both formal and informal community leaders, particularly those who have an understanding of the community history, values, and culture. Methods for gathering data from community members on assets are similar to other evaluation techniques, including interviews, focus groups, surveys, and secondary data analysis of economic, education, or health data. GIS mapping might also play a role in identifying existing structures, services, and resources.

Culturally relevant interviewing and assessment is critical to gathering quality data from these efforts; attention to language, interviewing techniques, body language, and the role and view of "outsiders" in the eyes of community members are all important considerations. For example, is it common for community members to share concerns with neighbors, or would they be more likely to speak frankly with a nonmember? Do spoken or unspoken social "rules" exist dictating who among community members may speak for the group? Do community members have particular ways of describing assets that might not resonate with a person who is unfamiliar with the community culture or history? Is the way that a person who is unfamiliar with the community asks questions that may elicit more or less information from community members?

Additional community strengths may be determined through utilizing secondary data sources, such as employment and labor market information, health data, and educational attainment data. Ratings of available services, safety, and natural resources may serve to highlight strong features of a community. Information on available housing units, average cost of property, number of businesses and how many people they employ, development projects and permits, use of open space, and much more is available through public records and archival data. These assets may be publicized and even used to leverage additional resources in the future (Community Tool Box, 2016).

Practitioners and scholars of the vocational rehabilitation counseling (VRC) profession may be left with the simple question: "Why and how is assessing for community strengths and weaknesses an important consideration when working with clients?" By understanding the strengths a community holds (i.e., strong community involvement, high demand for specific jobs, access to transportation, etc.) and weaknesses that currently exist (e.g., transportation barriers, lack of access to community resources, and insufficient job opportunities), rehabilitation counselors can capitalize on the strengths and counter weaknesses through a collaborative effort with their clients. However, facilitating change based off assessing for strengths and weakness is a community-based approach whereby stakeholders, governmental agencies, and community leaders are actively involved toward implementing positive change within their district. Yet, when community participation is absent and people of position in structural and social hierarchies oversee planning, implementation, evaluation, reporting, administration, and financial control, failures tend to occur among these stakeholders, often leaving residents in a state of dismay (Boutilier, 1993; Laverack, 2006; Syme, 1997). Furthermore, inequalities in health, and overall well-being, tend to be negatively affected when policy makers have too much control in the decision-making process; as a result, communities must have a sense of ownership and be empowered to address any concerns they possess (Laverack, 2006).

The importance of assessing for strengths and weakness within rural communities cannot be overstated. To illustrate this case and point, Averill (2003) conducted research in Grant County, New Mexico to identify a standard measure of community-based attributes and strengths that could eventually lead to positive change. Historically, this geographic region is an isolated mountainous and dessert terrain area with small communities consisting of several hundred residents within each. The economic conditions have traditionally operated through copper mining, cattle ranching, farming, logging, and now tourism, though challenges remain consistently problematic for these rural communities (Averill, 2003). Key issues or concerns identified by participants involved in the study included (a) prescription medications were typically elevated in cost, and accessibility and affordability for obtaining medicine were challenging; (b) limited access to healthcare, specialty care, hospice services, and emergency care was concerning for the elderly and their families; and (c) social isolation and loneliness due to living within remote areas were reported. Though the weaknesses conveyed have been repeatedly discussed throughout the text, the researchers identified three principle strengths found among this population for overcoming the barriers encountered and comprise of the following: (a) age, cultural diversity, economic, and vocational history led to increased knowledge for sustaining health, caring for sick and injured family members, and methods for reducing time away from work when confronted with illness; (b) healthcare professionals who decided to relocate or remain within Grant County were passionate about improving healthcare services through creative and problem-solving techniques, staying up to date with current practices within their medical field, and believed in community partnerships for positive change; and (c) community-based practices by planners, educators, advocates, healthcare providers, and individuals within administrative and leadership roles, actively participated in reducing fragmented service delivery (i.e., inadequate healthcare), increasing educational opportunities, and enhancing social services.

The resulting outcomes by which Grant County was assessed provide insight into a rural community that would normally be seen as disadvantaged based on barriers frequently encountered. Therefore, constituents must first identify the deficits/weakness to foster a healthy understanding of strengths frequently overlooked. It is not uncommon to focus exclusively on the weaknesses without regard to the resiliency for overcoming challenges identified earlier. Although there is no question that streamlining and improving services are crucial for the betterment of residents and the functionality of a community, recognizing strength-based characteristics can spur change in appropriate areas. For example, rather than assuming Grant County is in dire need of financial resources for educating families on caring for the sick, resources can be allocated to focus on problematic areas not countered through the strengths found among the residents.

Distinguishing Characteristics of Resilient Communities

In previous sections, we have presented aspects of community capacity that contribute to resilience. These have included both material assets (e.g., funds, natural resources) and people. In many communities, the residents and social infrastructure are the greatest asset. Social capital, defined as "relationships between people, characterized by trust and the normal of reciprocity" (Putnam, 2000 cited in Besser, 2013, p. 118), has been linked to higher levels of civic engagement, community cooperation, and quality of life among community members (Besser, 2013). Kulig et al. (2008) suggested in their model of community resiliency that community experiences and sense of belonging in the community drive a shared outlook among residents. Then, when community action, an event, or circumstance occur, members are better poised to come together to respond in a cooperative and unified way.

Social Infrastructure

The social infrastructure of a community influences the level of connectedness, shared values, and commitment of residents. Social infrastructure is defined as the place where the community functions (e.g., meeting places, community centers), where organizations are built and exist, and where social capital can develop (Flora, Flora, & Gasteyer, 2016). Locales provide public spaces where people are nurtured and relationships are formed. For some residents (e.g., those with human service needs), these public spaces may serve as important sources of social interaction in their lives. Examples of spaces that support social networks include faith-based centers (e.g., churches, temples, mosques), parks, tenant or neighborhood centers, youth organizations, health clinics, child-care programs, libraries, and schools. In rural areas, these places may be spread out or may be situated centrally and a distance from many residents' homes, making transportation a potential barrier to participation if it is not available.

Flora et al. (2016) described two kinds of social capital that may serve to enhance community cooperation among residents: bonding and bridging. Bonding social capital is the relationships between groups of individuals who share a common identity or ideology. Bridging social capital is the relationships that exist between members of diverse groups of people. In some rural communities, there is little diversity among members, thus decreasing the need for bridging social capital. Bonding social capital is more effective at motivating people to come together and volunteer time and effort to reach group goals. In communities where multiple groups of people exist, having high levels of bridging social capital and moderate levels of bonding is most advantageous in supporting cooperative work toward a community vision, which is a key aspect of resilience (Flora et al., 2016).

Community Pride

In many rural communities, residents share a sense of pride in where they are from. This pride emanates from a sense of shared values (e.g., "small town values") among community members. Rural communities cultivate a strong sense of history, beneficence, purpose, autonomy, and respect for others (Hoffman, 2011). Interviews with rural residents who left and then returned to their communities revealed several important draws and aspects of community pride (Cromartie, von Reichert, & Arthun, 2015). Residents valued connections, raising children near their extended family, peace and safety, and opportunities for outdoor recreation. The lifestyle in rural areas is described as, "clear skies, slower pace, clean air, and close social networks" (Coll & Haas, 2013, p. 103), giving residents much to be proud of.

Rural residents are also proud of their values and the people who live in their communities. Often their pride comes from juxtaposing rural residents and their values against urban dwellers. For example, they consider themselves to be patriotic, God-fearing and religious, honest and law abiding, hardworking, and democratic. They consider city residents to embody the opposite of these virtues: un-American, lazy, corrupt, secular, and heavily controlled by those running industry (Flora et al., 2016). The cultural capital they perceive as rural people provides them with pride in where they are from and a strong desire to stay where they believe the people are "good."

Sense of Belonging

Rural residents, particularly in small towns, share a sense of belonging and value for social connections. It is considered part of human nature to readily develop social bonds and attachments under a wide variety of conditions (Baumeister & Leary, 1995), and the conditions of small town, rural life, are certainly amenable. Particularly in the circumstances of scarce resources, it is often in the best interest of all to cooperate and share resources so that everyone can benefit and be protected from external threats. Social psychology researchers have also found that proximity matters in forming social bonds; we are more likely to develop relationships with those we live near or spend much of our time with (Baumeister & Leary, 1995).

Community Action and Civic Engagement

This shared sense of belonging also influences residents to get involved in community activities, and civic engagement is considered by some to be an expectation. Everyone needs to take a turn and contribute (Cromartie et al., 2015). Communities are often making decisions about needs and what infrastructure to invest in. Choices such as water supply, public spaces, schools, waste processing, landfill space, and maintenance of roads and bridges are some examples of decisions that communities must make based on their shared values. As a result of the Omnibus Reconciliation Act of 1981, federal support of local communities was drastically reduced (Flora et al., 2016). Previously, rural community governments relied on the general revenue-sharing stipulations to assist with their local budgets, and this stipulation was eliminated in 1987 (Flora et al., 2016). This leaves rural community leaders with less support from the federal government than before and with greater responsibilities for local infrastructure. Resilient communities stand apart from others in their level of planning, investment, and cooperation in addressing these challenges. Much of their success comes from the shared sense of responsibility that residents feel to get involved with community activities and civic engagement.

Residents

Rural residents are as varied as those living in other regions, and the traits outlined in the following sections are considered along a continuum. These points are not meant to assume that all rural residents feel, behave, and believe the same ways or are ubiquitous people. However, several themes among resilient communities are highlighted in the following sections in an effort to celebrate the strengths of rural residents that have not been historically recognized.

Outlook or Mentality

Rural residents have long celebrated a different outlook or mentality than those who live in the suburbs or rural areas. This worldview is closely tied to the rural experience, which "has allowed them to retain a physical and mental toughness and to preserve a code of commitment to family and kin that has long ago boon lost in the rush to a commodified human existence" (Harkins, 2004, p. 206). Residents look back on difficult circumstances with pride and recognition of the rewarding aspects of their experiences, even lamenting their way of life as "disappearing" (Harkins, 2004). While rural areas and residents are not disappearing, the shift toward urban life as the reference point reduces the cultural visibility of rural living in media and popular culture (Ching & Creed, 1997). In addition to commitment to family, rural residents also have a respect and reverence for their natural surroundings that is often absent in their urban or suburban counterparts.

Many residents have learned that if they are to achieve something, it will be because of hard work and the support of their family and neighbors. They invest in their homes, properties, and community in order to build a legacy for their children and future families. Sacrifices and going without are in favor of future sustenance. They may have a mistrust of persons in power and outsiders because of past interactions where they lost or had things or people taken from them by governments, banks, or private industry (Flora et al., 2016). They rely on their faith, resilience, dedication, and family to continue to meet their own needs.

Coping with Adversity

Various fields of study operationalize and conceptualize resilience and coping as two separate entitles. The concept of resilience is increasingly used to investigate the dynamics and processes that help individuals deal with hardship. Coping on the other hand continues to be conceptualized as the cognitive and behavioral responses of individuals to deal with hardship (Skovdal & Daniel, 2012). Coping is broadly defined as "expending conscious effort to solve personal and interpersonal problems and seeking to master, minimize or tolerate the stress of conflict" (Srivastava, Singh, & Srivastava, 2014, p. 218). The level of coping an individual may exhibit is influenced by maturity, experiences, and opportunity. Research suggests that coping is also influenced by, but not limited to gender, age, ability/disability (including type of disability and age of onset), educational level, social networks, poverty, and health status. Coping and resilience are not expressed or employed uniformly among rural residents or communities, whereas some people may rise to the challenge others may fold under the pressure.

Rural residents face multiple adversities that place ongoing stress on them including financial hardship, natural disaster, isolation, limited services, and lack of transportation. These multiple stressors require rural residents to have social support in the community. Bushy (2000) identified three levels of social support from a rural perspective: (a) support volunteered by families and friends, (b) local emergency services and community and religious organizations, and (c) formal services, which usually require a fee. Letvak (2002) stressed that it is the quality of support that is available, not the quantity for many rural residents. The majority of rural residents usually select the first two levels of support.

In a study of stress factors that are unique to rural police officers, Oliver (2004) found that in addition to the stress that urban police officers face, such as organizational, external, task-related, and personal stressors, rural and small town officers also face security because of geographic isolation (and limited number of officers), social factors (everyone they encounter while off duty knows they are police officers), working conditions (low pay, inadequate equipment and training), and inactivity stressors (long period of boredom, low crime rates, resident reluctant to call the police). Although many of the observations in the study were not associated with high levels of stress, a number of critical areas were suggesting that initiatives need to be taken to address these unique factors.

Coping involves both negative and positive strategies. In a study of social support, coping, and medication adherence among rural HIV-positive women, Vyavaharkar et al. (2007) found that coping by denial/avoidance was a predictor of nonadherence to medication, which was an unexpected result. Conversely, the study found the participants that engaged in more active coping in response to HIV-related life stressors were more likely to adhere to their medication regimen, which was an expected outcome. In addition, the use of spiritual activities by participants mediated the effect of social support on medication adherence. Among rural clergy in England, Brewster (2012) found that for clergy who were responsible for three or more rural churches, the most frequent coping strategies are self-controlling, planful problem-solving, and positive reappraisal. The strategies used less frequently are seeking social support, distancing, accepting responsibility, and escape avoidance. Gratitude as an affective trait, often culled through religiosity, is also negatively correlated with psychological disturbance and positively related to well-being, positive affect, and satisfaction with life (Rosmarin, Pirutinsky, Greer, & Korbman, 2016).

In rural communities, coping with adversity is considered as ingrained in both culture and communities. For example, one of the hallmarks of coping with adversity in rural areas was the great depression. Some believe that the depression in rural America began almost a decade before the great depression and as urban areas quickly recovered and gained economic growth, rural areas never recovered. Some rural residents were able to maintain their land and grew food on which to live, while other moved away. Both of these outcomes demonstrate a coping response of rural residents to their situation. Resilience, a key feature in coping, is both an individual characteristic but can also be relationally developed. In studies of children raised in difficult circumstances, a subset of children grew up to be successful adults who "worked, played, and loved well" (Walsh, 2003, p. 2). Some of the successful adults had even experienced trouble during adolescence but credited a person, or a faith community, as influencing them positively and helping them develop resilience. In another study of rural youth, supportive educational settings and strong adult role models were credited as building resilience among at-risk youth (Curtin, Schweitzer, Tuxbury, & D'Aoust, 2016). In close-knit rural communities, residents can help each other build resilience through contact, encouragement, and involvement.

Getting Along and Creating Networks

Rural residents, by definition, live in areas with lower population density, meaning that there are fewer choices for making friends and acquaintances. This often means that most people know each other, and there is reduced anonymity and privacy compared to what it is like living in areas with greater population density. Slama (2004) referred to this experience of little privacy as the "fishbowl phenomenon" (p. 10). This familiarity has some drawbacks (e.g., people may be less prone to express unpopular opinions, greater stigma for those who do not fit social norms) but also has some benefits. Rural residents in small communities are apt to be familiar with the needs of their neighbors, and this often mobilizes support and assistance when it is needed (Leipert & George, 2008). For example, residents may take up a collection, offer transportation, or bring food or other material goods to families when a crisis occurs. Often this help comes without the expectation of recognition or praise and from people who have limited resources themselves. For some, rural culture may represent more traditional gender roles and social norms, which may be problematic for some members who are nonconforming. For example, Leipert and George (2008) reported results of qualitative interviews where residents were asked to describe rural values and community pride, and participants shared narratives of male dominance and judgment and shunning of those who did not fit in to social norms. In some small rural communities, people are intolerant of differences, and distrusting of outsiders makes it hard for some people to fit in (Leipert & George, 2008). Despite these difficult circumstances, overall, rural culture is community oriented, and residents often share a commitment to helping others. This culture of helping each other allows for greater resilience in times of crisis.

Recommendations for Service Delivery

As you have learned in other chapters, persons with disabilities are overrepresented in the rural population—some estimates that more than one in five residents in rural areas have a disability (Seekins et al., 2011). Resilient communities are strengthened by the ability to serve and provide assistance to their neighbors. Those with access to rehabilitation and human services are in better positions to help meet the needs of the community; however, professionals practicing in these areas must be attuned to strategies and approaches to partnering with community members for greater effectiveness.

Importance of Relationship Building and Working Alliance

For professionals working in rural communities, the importance of relationship building is clear. As we have mentioned, rural communities come with their own unique cultural norms and expectations, and learning these ways of communicating and relating is critical to working well with residents (Slama, 2004). If you are an "outsider" to a community, building trust may take some time. Methods designed to get to know residents and learn about the community will help build trust, although patience is necessary to allow these relationships to develop. Chipp et al. (2011) suggested that providers get to know elders and respected residents who can help them understand the community and needs better. This will in turn result in gaining the respect of others. Authors cautioned new practitioners against isolating, recommending they spend time in the community (attending church, going to market, volunteering, attending community events) and get to know their neighbors. Providers who isolate are often rejected, as this goes against the value of community. In some cases, a provider may have to repair mistrust from past providers whose missteps left hurt feelings or unfulfilled promises. Being flexible and taking on extra responsibilities as needed will also help to develop social capital and trust among community residents.

Collaborative Service Models

Examinations of rural health disparities have demonstrated individual "neighborhood effects" are evident in population studies of community health (Hartley, 2004). The assumption that rural culture is based on an agrarian history and ignores other cultural differences does not help us address health and health disparities in modern rural America. Findings illuminated regional differences in health consequences for rural residents, prompting examination of the questions, how do local cultures differ from one region to another, how can we detect these differences, and how can we use this knowledge to improve health (Hartley, 2004)? Public health and medical officials have addressed some of these challenges by collaborating with community groups and individuals in order to more efficiently and effectively meet the health needs of rural residents. Some of the challenges addressed by these collaborative health models included limited access to financial resources, trouble recruiting and retaining staff, inadequate transportation resources to cover the broad geographic areas, and smaller hospitals with limited resources for treating patients (Berkowitz, 2004). "Turning Point" grants, funded by the Robert Wood Johnson and W.K. Kellogg Foundations, resulted in several successful collaborations that brought services and resources to underserved areas with high rates of poverty and health inequity (Berkowitz, 2004). Community residents and organizations were paramount to ensure that community concerns were addressed adequately and took lead roles in grant writing and fundraising. Including residents in these planning efforts is critical to identify aspects of community culture that are supportive of, or provide risk to, health of residents.

Social Valorization Within the Consumer's Community

Rural communities foster a culture where people "take care of their own." This may come in the form of "closing ranks" around a person with particular needs, especially those who may be considered vulnerable. This culture of care and protection is well-intentioned, but may limit the perception of a person being capable of contributing to a given community. Social valorization is the idea that in order to achieve full inclusion into a society, one must hold a valued social role within their community (Wolfensberger, 1983). In some rural areas, people who have disabilities are assumed to be "a drag on the economy," unable to work, and only contributing financially via disability benefits (Seekins et al., 2011). How others treat us is a reflection of our value in their opinion, and this in turn influences the way we behave. When others treat us as though we are capable, we are more likely to assume this role and are apt to achieve more (Wolfensberger, 1983). In a community where people are very familiar with one another, it may be difficult to change an image of a person to allow for assuming a role with greater social value. Wolfensberger suggests several strategies to enhance the social image of a person including enhancing competency, addressing needs, introducing age and culturally appropriate activities and schedules, and ensuring autonomy and promotion of rights. Close attention to the language used to talk with, and about, this person is also important to ensure that devaluing messages are not being sent inadvertently (Wolfensberger, 2000). An individual may leverage existing relationships (e.g., family, friends) to identify and access activities that the person would like to assume and they believe would be considered of value to the community. In fact, rural residents with disabilities are more likely than the general population to be self-employed and serve in elected roles and as volunteers (Seekins et al., 2011). Accessible arrangements can facilitate continued community participation for many residents who have disabilities, thus enhancing the human capital and community capacity.

Building Social Capital and Social Networks

Social capital is defined as the relationships between people living in a particular society. When one person values another and cares about their well-being, successes, failures, and so forth, there is said to be high levels of social capital between them. The idea that your success is my success, for example, would indicate high social capital. For strangers, there is little and perhaps no social capital expected (Robison & Ritchie, 2010). Social capital and social networks are incredibly important in our lives; leveraging these relationships is often how we find employment opportunities, garner social support, and pursue shared goals (Phillips, Robison, & Koscuilek, 2014). For those who have small social networks and struggle to connect with others (e.g., because of disability, personality traits, or environmental factors), indirect social capital may become important. Findings indicate that social capital can be "inherited" and used to the advantage of a person other than it previously belonged (Phillips et al., 2014, p. 38). This may be in the form of employment opportunities, wages, or other goods or services. The idea that social capital can be "shared" or used to benefit another person is important in a rural community where social capital is often high between residents. A service provider working with an individual may encourage them to think about their list of family members, friends, and other social connections and consider who might be willing to help them—either directly or indirectly by reaching out to another person on their behalf.

Similarly, a professional who is new to a community may seek to build their social capital by investing in relationships with other residents and find mentoring or other guidance from someone who is highly valued and respected within the community. Relationships are important everywhere, but this is especially true in rural towns and communities.

Building Natural Supports

The most effective and long-lasting supports provided to individuals in need of human services come in the form of "natural supports." All of us need some level of support to succeed and some more than others. Natural supports are most often considered part of existing relationships in a person's life, for example, assistance garnered from a friend, family member, or coworker as opposed to a paid professional (Wehman & Bricout, n.d.). Natural supports are most often discussed related to employment but may also serve to encourage a person to take a more active role in the community or fulfill some other personal goal. In communities where residents are highly interdependent, natural supports are already a fact of life and constantly occurring. Stepping in to help a friend or neighbor when it is needed, with the expectation that you can count on the same kind of support in return, is very consistent with the provision of natural supports. In rural communities, finding transportation, learning a new skill, or locating a needed item are things that you may naturally think to pick up the phone or go next door to see about. For individuals with smaller social networks, helping them identify people in their community or at work who might be willing and able to help them with something may be the only way to get that need addressed.

Community Advocacy to Address Needs

In rehabilitation and human services, advocacy is ongoing to help meet the needs of service participants. In rural communities, this may require community advocacy to find a way to address gaps in availability and/or major barriers, and these needs may be shared more by residents than service recipients. For example, increased funding for community infrastructure, safety initiatives, or supports may be worthy causes that members of the community can share as a common goal. Common challenges, such as crumbling infrastructure, water supply safety and health, and availability of reliable and affordable utilities (e.g., internet access), are all targets of community action that impact all residents. For some, the financial burden incurred by not being able to rely on these basic services can mean the difference between getting by financially and needing to rely on outside help to meet their basic needs (Flora et al., 2016).

Saul Alinsky developed an approach for community organizing that has been replicated and modified in both urban and rural spaces nationwide (Flora et al., 2016). His approach, called the "power approach," is based on the idea that power must be taken; it is not freely given away by those who have it. The goal of the power approach is to unify to allow people who are not in positions of power access to the ability to change their circumstances via the power of the group (i.e., "power in numbers"). Leadership (sometimes by an outside organizer) is necessary to facilitate the process of airing grievances and identifying issues to be resolved. Another critical aspect is identifying talents of group members that can be harnessed to further the cause. The group must gather necessary information on the scope of the problem, related issues, and available resources that can be applied to ameliorate the gap. Political advocacy becomes necessary once resources have been identified (e.g., state funding) to convince those who are capable of making the necessary changes to act (Flora et al., 2016).

Involvement by relevant community members is essential to fully understand the scope of the problem and help to evaluate possible actions. For example, if a need is identified for greater accessibility so that people who use wheelchairs and other mobility devices can get around safely and independently, residents who use these mobility aids must be part of this effort.

Otherwise, it is unlikely that the situation will be understood and effectively addressed since those who are most knowledgeable of the scope of the problem and most effected were not consulted.

Future Implications

Building and maintaining community resilience in rural communities is an ongoing challenge. It takes the combined efforts of community leaders, residents, practitioners, and researchers. In addition, community resilience requires resources to sustain an effort beyond a single point in time. The question is how do rural communities leverage their assets today to be competitive in the future? Heijman, Hagelaar, and Heide (2007) examined rural resilience in terms of rural economic, ecological, and cultural systems as increasingly entangled, and the interactions between these systems suggest "changes in one domain of resilience can affect resilience in the other domains" (p. 384). To that end, future development of rural resilience for rehabilitation and other social and human services should be considered within the complexity of the relationship between rural competitiveness, regional specialization, and geographic typography. Because both resilience and sustainability deal with the future (Heijman et al.), rural resilience invites the exploration of potentially different balances and combination of services within a rural area.

Rural community resilience is strengthened with alliance building between practitioners and the communities they serve. Thus, service providers should look to nontraditional outlet in which to expand services and reach rural clients. One such example is to borrow from the ideas for building resiliency in small town grocery stores from the Rural Grocery Summit. According to Nyquist (2016), as rural towns decrease in population size, it becomes more difficult to provide the basic services offered in larger communities (e.g., post offices, libraries, banks, health clinics). The disappearance of these retail-based services is now reappearing inside the grocery store. Offering these services provides vital services to the community. Through a partnership with public service agencies and healthcare providers, the grocery store is now an emerging means of service delivery (e.g., telemedicine, information kiosk) for access to service providers for those without transportation (Nyquist). The grocery store approach also can be applied in rural communities through the use of agriculture extension offices, which usually exist within each county. These extension offices can serve as locations for clients to meet appointments and information dissemination.

Future efforts to enhance and strengthen resilience of rural areas will need to address resilience at three levels: individual, group, and community. Lyons et al. (2016) found that fostering the development of groups can be an important part of increasing community participation and improving health and well-being outcomes in rural communities. In another study, Steiner and Markantoni (2013) found individual social resilience strengthens the community, thereby enhancing the overall resilience. Although community social resilience was found to be stronger than individual and community economic resilience, it was weaker than individual social resilience. The conclusion was that while overall resilience is the combination of all dimensions and levels of resilience, a community might face specific challenges related to social or economic dimensions and to individual or community levels. Resident in locations with more diversified services and resources reported being more resilient (Steiner & Markantoni). In addition, regional differences should be considered as well because location is as influential in resilience as culture. In fact, "there is nothing uniquely rural about the term resilience since it has also been adopted in the urban context, arguably with even more fervor" (Cheshire, Esparcia, & Shucksmith, 2015, p. 7). The study by Wells (2010; See Research Box 7.1) indicated that location was not as much a function of resilience as was income level. In the future, resilience should be defined beyond more than empowering people to endure hardships.

Research Box 7.1

See Wells (2010).

Purpose: To determine if (1) resilience levels vary in older adults living in rural, urban, or suburban areas, (2) the relationships of sociodemographic factors (age, income, education, marital, and employment status), social networks, health status, and resilience vary with the location in which older adults live.

Method: A cross-sectional design was used. Data were collected from 277 registered voters aged 65 years or over who lived in rural, suburban, or urban locations in New York State. The instruments used were the resilience scale, the SF-12v2, and the Lubben Social Network Scale—revised.

Results: No differences were found in resilience levels across the three locations. In regression analysis, stronger family tie networks, lower household income, and good mental and physical health status were found to be significantly associated with high resilience levels.

Conclusion: The location in which older adults reside did not affect resilience. The surprising association with resilience was low income. Mental health status was most strongly associated with resilience in older adults. Screening older adults for resilience levels and intervening when low levels are identified by implementing strategies to build resilience may be clinically relevant; however, further research is needed.

Questions

1. What were the sampling biases of participants in this study?
2. How might replicating this study with a more diverse population change the results?
3. What other variable(s) would you include in this study?

Finally, in advancing resilience in rural communities, Dagdeviren, Donoghue, and Promberger (2015) suggested it is prudent to consider the problems of neglecting the social conditions of resilience. That is, while resilience is usually assigned positive attributes such as successfully adapting to adversity or transforming oneself to a better state for some, these same attributes may result in a culmination of social exclusion and highly restrictive institutional barriers for households with severe disability or mental health problems. Dagdeviren et al. further explained the consequences of neglecting the social conditions of resilience for individuals who are more disadvantaged as:

> Their chances of 'beating the odds' against economic adversity through individual action is likely to be circumscribed by disadvantages they confront on a daily basis. How should resilience or a lack of it be judged in households like this? Moreover, there may be cases where a display of resilience in the form of speedy recovery from unemployment and poverty is a manifestation of a middle-class ability to navigate through the system.

It is about action planning to better utilize human service agencies to organize, collaborate, and provide integrative services in rural and remote settings.

Summary

As economic conditions evolve, weather patterns change, and resources flux, rural communities will continue to adapt and change as well. Rural communities are often lamented for difficult circumstances, but the resilience and strength associated with small towns and communities must not be overlooked. Community organizing and development is critical to help build more resilient communities. Residents who are empowered to assess strengths and weaknesses, set goals, and advocate for their needs are better equipped to respond to both anticipated and unexpected crises and setbacks. Utilizing public spaces to help residents connect and build relationships encourages greater development of social capital for all residents, also increasing the likelihood that residents will know and be familiar with one another's needs in times of crisis. Planning ahead for events (predictable or not) also helps communities to respond more effectively. Community resilience is most evident in the times following an adverse or emergency event.

Professionals working in rural communities may have a role in fostering resilience in both clients and the community. One approach is to identify and build upon existing strengths. Community members are the best informants on strengths and barriers within a community; many already have associations or small government improvement groups that a professional may get involved with. Knowledge of resources, such as grants or other financial opportunities, and how to access them, may be of great help to a group that already has an agenda. At the individual client level, helping clients connect with their family, friends, and neighbors in a way that helps them leverage their social capital and maintain a valued social role within the community is important. Some of the greatest resources in a community are the people and the tradition of coping through adversity and taking care of each other.

Resources

Building Resilience in Rural Communities Toolkit: http://learningforsustainability.net/pub/BuildingResilienceinRuralCommunitiesToolkit.pdf

Housing and Urban Development: Promise Zones Initiative http://portal.hud.gov/hudportal/HUD?src=/program_offices/comm_planning/economicdevelopment/programs/pz/overview

National Association of Development Associations: Vibrant Rural Community Case Studies https://www.nado.org/vibrant-rural-communities-case-study-series/

Rural Development Initiatives: http://rdiinc.org/newsletters/2014-10/how_resilient_your_rural_community

The Community Resilience Manual: A Resource for Rural Recovery & Renewal: http://communityrenewal.ca/sites/all/files/resource/P200_0.pdf

World Food Programme Rural Resilience Initiative: https://www.wfp.org/climate-change/initiatives/r4-rural-resilience-initiative

Learning Exercises
Self-Check Questions

1. List and describe some common challenges associated with rural communities (i.e., Grant County, New Mexico) and how rehabilitation counselors can work with persons with disabilities to overcome these issues.
2. The chapter discusses residents and social infrastructure as two of the greatest assets to a rural community. What other factors increase a rural community's strengths? What contributes to its weaknesses?
3. As a rehabilitation counselor, what recommendations would you have for consumers toward building natural supports to overcome difficulties commonly faced (i.e., transportation)?

Experiential Activities

1. Take a tour of your town or community. Assess transportation, architectural accessibility, safety, ease of getting around, and availability of necessary services (e.g., grocery, laundry, goods and services, medical care, mental health, education and vocational preparation, available housing, affordability, job prospects). List the top strength and the top weakness of your community.
2. Interview the person you know who has lived in your community for the longest period of time. What can they tell you about community strengths? What do they see as the greatest challenges for residents? If they were asked to lead a community initiative, what would they try to improve?

Multiple Choice Questions

1. Which of the following defines the term resilience?
   - (a) The ability to bounce back after adversity
   - (b) Taking the good with the bad
   - (c) Knowing when it is time to give up
   - (d) A strength that most people do not have
2. Which of the following best describes coping?
   - (a) Putting up with something long enough
   - (b) Trying to forget about your problems
   - (c) Utilizing strategies to minimize the consequences of stress
   - (d) Exercising instead of worrying
3. Which of the following describes one of the greatest strengths of rural communities?
   - (a) Poverty
   - (b) Low taxes
   - (c) Close social networks
   - (d) Higher rates of disability
4. Urbanormativity refers to which of the following?
   - (a) Cultural norms in the USA are based on rural areas
   - (b) People in rural areas are more normal than urban residents
   - (c) Cultural norms in the USA are based on urban areas
   - (d) Suburban residents set the standard for US culture
5. If a counselor is not familiar with the social landscape of a new service area, how might he or she gain the trust of people in a new community?
   - (a) Develop relationships with elders and leaders
   - (b) Door-to-door introductions
   - (c) Counselors need to know their own clients
   - (d) Move to the center of town
6. What is the benefit of residents leading community advocacy efforts?
   - (a) Cost-effectiveness
   - (b) Awareness of strengths and weaknesses
   - (c) Legality
   - (d) There is no benefit
7. Which of the following best describes social capital?
   - (a) Knowing a lot of people
   - (b) Being able to raise money
   - (c) Your values as a person
   - (d) The value of social connections
8. Which of the following is a common expectation in rural communities?
   - (a) Neighbors help each other
   - (b) Everyone has responsibility in the community
   - (c) We take care of our own
   - (d) All of the above
   - (e) None of the above
9. Which of the following is a common challenge in rural communities?
   - (a) Natural disaster
   - (b) Economic depression
   - (c) Crumbling infrastructure
   - (d) All of the above
10. An approach to supporting persons with disabilities at work without the help of professionals is known as which of the following?
    - (a) Environmental validity
    - (b) Natural supports
    - (c) Friendly neighbors
    - (d) Independence

Key

1 – A
2 – C
3 – C
4 – C
5 – A
6 – B
7 – D
8 – D
9 – D
10 – B

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Part II

Select Populations with Disabilities in Rural Settings

8

Challenges Faced by Veterans Residing in Rural Communities

Noel A. Ysasi and Bradley W. McDaniels

Overview

As discussed throughout the text, rural and urban communities differ primarily in three ways: the demographic composition, social ties and social capital, and infrastructure and institutional support (Hofferth & Iceland, 1998). For the veteran, this poses significant challenges when reintegrating into civilian life which is generally problematic and complex regardless of where a veteran resides post military discharge. Case in point, non-veterans are afforded the opportunity to choose a healthcare provider, a medical specialist (optometrist, cardiologist, etc.), and a postsecondary educational program/institution and generally have stable employment. In contrast, the veteran is confronted with overwhelmingly low odds of successful reintegration. Specifically, when not outsourcing, veterans are faced with limited healthcare options that are provided solely through the Veterans Health Administration (VHA) and often must travel great distances to receive services. Additionally, veterans seeking a postsecondary education, and/or employment, must attend an approved educational program, which is less available in rural areas, and are faced with obtaining employment with limited options that often does not translate well from their military experience. These challenges can also carry over to the spouse and/or child during the early reintegration phase from military to civilian life.

An important consideration for mental healthcare providers and vocational rehabilitation counselors are the demographic characteristics outlining this population. For example, the greatest percentage of service members residing in remote areas often come from the branches of military with infantry units (i.e., Army and Marines), which are at increased risk for direct combat exposure, often leading to high rates of physical and mental health issues. Among the counseling professions, it is agreed that to provide effective counseling services to diverse populations, understanding the specific population for which one is counseling is necessary for successful therapeutic outcomes to occur (U.S. Department of Health and Human Services, 2006). Therefore, we provide details in each table outlining the demographic characteristics, common mental health disorders, and physical disabilities among rural and urban veterans for the vocational rehabilitation counselor and mental health clinician.

N.A. Ysasi (✉)
College of Health and Human Services, Rehabilitation Services and Rehabilitation Counseling, Northern Illinois University, DeKalb, IL, USA
e-mail: nysasi@niu.edu

B.W. McDaniels
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA

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Learning Objectives

Upon completion of this chapter, readers should be able to:

1. Understand the history and legislation affecting the veteran population.
2. Recognize the general demographic characteristics of rural and non-rural veterans.
3. Be able to identify the mental and physical health conditions affecting the veteran population.
4. Be able to identify common barriers hindering rural veterans from receiving services provided by the U.S. Department of Veterans Affairs.

Introduction

As discussed throughout the text, rural communities bring about unique challenges (i.e., access to public transportation) often affecting its residents. How local government and citizens of rural territories respond to any challenge is largely dependent on demographic characteristics of the population and community infrastructure (i.e., culture, age, community resources, economy, and employment opportunities). Prior to 2006, however, inadequate attention was placed on veterans, active military, and National Guard, who occupy these rural territories. To date, approximately 5.3 million (24%) of veterans reside in rural areas, many of whom return home to reconnect with family and friends (Office of Rural Health [ORH], 2014). Upon returning home, many experience an array of mental illnesses (i.e., depression, posttraumatic stress disorder, substance abuse disorder) and physical health problems, generally, as a consequence of deployment. Unfortunately, when veterans and active military seek healthcare services to address these concerns, they often encounter a vast number of barriers (i.e., long distance to a Veteran Affairs Medical Center), ultimately affecting quality of life. For the purpose of this chapter, we address the needs of the veteran and military culture by exploring historical and current legislation, overall healthcare needs, psychosocial adaptation challenges, and necessary resources for healthcare professionals aiding this population toward successful civilian reintegration.

History of Veteran Legislation

When thinking of the U.S. Armed Forces and our veteran population, it might appear as if this population has been treated with kindness and afforded exceptional assistance through various educational and healthcare benefits. However, prior to World War I, early legislation focusing on veterans receiving disability compensation, medical health coverage, and vocational rehabilitation did not exist. The first government-funded programs were initiated through the Smith-Hughes Act of 1917 and the Soldier's Rehabilitation Act of 1918. Even during this time, veterans experienced extreme difficulties transitioning into civilian life either as a result of "shell shock" (now referred to as posttraumatic stress disorder), combat-related physical disabilities, or unemployment. With the arrival of the Great Depression, veterans were experiencing extreme hardships. In 1924, the World War Adjustment Compensation Act was passed which allowed veterans to receive $1.00 a day for service rendered stateside and $1.25 for overseas service (Woodward, 2014). Although this endowment policy would not become payable to the veteran for 20 years, unless the veteran died prior to 1945 in which case, the veteran's family would be paid (U.S. Department of Veterans Affairs [VA], 2015a). In protest, over 20,000 Veterans accompanied by their spouses and children would descend on Washington, DC. As the march persisted, veterans and their families would establish camps and live in shacks and abandoned buildings, many of whom became sick with diarrhea, dysentery, and influenza, as a result of unsanitary living conditions. When veterans refused to return home, President Hoover deployed federal troops equipped with tanks and bayonets to disband the march, leaving many injured from bricks, clubs, or bayonets (Woodward, 2014). Not until 1930 would the veterans Administration become established to provide medical services, life insurance, and retirement payments for officers and civilian employees; eventually financial compensation for WWI veterans would be provided in 1937. In 1940, the Selective Training Service Act was enacted and afforded all persons who served, be guaranteed reemployment. Subsequently, the Disabled Veterans' Rehabilitation Act of 1943 was established. This would provide vocational rehabilitation for World War II veterans that acquired service-connected disabilities; over 621,000 veterans would become employed as a result of this legislation (Department of Veterans Affairs [VA], 2006).

As demonstrated through our brief yet extensive overview of historical legislation, improvements to ensure veterans and active military receive appropriate medical, vocational, and educational services have ensued; nonetheless, the passing of these acts has been reactive rather than proactive. Efforts to spearhead new bills are often politically based, the result of social media (i.e., coverage on inadequate access to healthcare), research driven, military conflict as a context for congressional action, or all of the above. For example, once the general public became aware of the high incidence rate of sexual assault among female service members, efforts to assist these women (i.e., through sexual trauma counseling) were determined to be insufficient. In addition, efforts to reduce waiting times among veterans seeking healthcare services was not a top priority until social media released documentation revealing veterans had often waited more than 6 months to see a healthcare provider. This, too, has been the case for veterans and active military living in rural territories. When research revealed rural veterans were experiencing significant transitional barriers in comparison to urban hubs, the Rural Rehabilitation Act of 2006 was introduced to Congress for the following reasons: (a) veterans living within rural settings have lower health-related quality of life (HrQOL) scores, (b) healthcare needs have not been adequately met, (c) higher proportion of casualties found among rural veterans as a result of recent conflicts (i.e., Operation Iraqi Freedom [OIF], Operation Enduring Freedom [OEF], Operation New Dawn [OND]), and (d) to establish up to five centers of excellence for rural health research, education, and clinical activities (Kane, 2006; Rural Veterans Care Act, 2006; Wallace, Weeks, Wang, Lee, & Kazis, 2006; Weeks, Wallace, Wang, Lee, & Kazis, 2006; Weeks, Wallace, West, Heady, & Hawthorne, 2008). Unfortunately, the bill would ultimately die on the senate floor. Nevertheless, the Veterans Benefits, Health Care, and Information Technology Act of 2006 would be signed into law, which incorporated selected language to address certain needs of rural veterans, National Guard, and the Reserves. A detailed outline of the Act of 2006 can be found in Table 8.1.

Of particular importance, the Office of Rural Health (ORH) would be established as a result of the Veterans Benefits, Health Care, and Information Technology Act of 2006, which aims at reducing barriers and enhancing services to veterans who reside within rural and highly rural areas. See Table 8.2 for a detailed outline of the services provided under the Office of Rural Health. Although the U.S. government has made significant improvements since 1917, the needs of this population are still profound. The Rural Veterans Improvement Act would ultimately be proposed to expand services specifically for the veteran population residing within rural territories; however, congress would deny its enactment in 2013, 2014, and 2015.

Rural-Urban Classification System and Veteran Demographics

In comparison to the standard rural-urban classification system discussed in previous chapters, the Veterans Health Administration (VHA) developed a classification scheme for designating locations throughout the United States as either urban, rural, or highly rural and coded as U/R/HR, respectively. The VHA developed this classification scheme based on census tracts and counties whereby urbanized areas are designated

Table 8.1 Veterans Benefits, Health Care, and Information Technology Act of 2006

Section	Description of services to be provided
Section 212. Office of Rural Health	Office of Rural Health is established; in cooperation with medical, rehabilitation, health services, and research programs, will conduct, coordinate, promote, and disseminate research into issues affecting veterans living in rural areas
Sec. 7308. Office of Rural Health	To assess the effects of the implementation of the fee-basis healthcare program on the delivery of services for veterans residing in rural areas; plan to improve access and quality of care no later than September 30, 2007
Sec. 213 Outreach Program to Veterans in Rural Areas	The secretary of Veterans Affairs shall conduct extensive outreach programs to identify and provide information to veterans served in OIF or OEF and who reside in rural communities, and the secretary must coordinate with local employers, state agencies, community health centers in rural areas, critical access hospitals in rural areas, and units of the National Guard and other reserve components based on rural areas to increase awareness of availability of healthcare
Sec. 214. Pilot Program on Improvement of Caregiver Assistance Services	Mechanisms to expand and improve caregiver assistance services; allocation of funds should be given special consideration to rural facilities
Sec. 822. Business Plans for Enhanced Access Outpatient care in certain rural areas	Enhanced access to outpatient care, primary care, mental healthcare, and specialty care is to be provided in the following areas: Lewiston-Auburn area of Maine; Houlton, Maine; Dover-Foxcroft, Maine; and Whiteside County, Illinois

Source: Veterans Benefits, Health Care, and Information Technology Act of 2006, Pub. L. No. 109–461. Stat. 3403

Table 8.2 Office of Rural Health and Six Primary Areas of Focus

Areas of focus	Vision
Access to Quality Care	Efforts to reduce barriers by improving transportation access and quality related to healthcare delivery
Technology	To identify gaps in telecommunications in infrastructure, telehealth services, equipment in rural and highly rural areas; to identify priority areas of care in rural and highly rural areas that could significantly be impacted by instituting new telehealth services; and to develop safe and cost-effective delivery of care via telehealth through the expansion of current services and piloting new initiatives
Studies and Analysis	To study and assess the effectiveness of pilot programs initiated through the ORH
Education and Training	Plan: To improve availability of education and training for VA and non-VA service providers to rural and highly rural veterans, to conduct rural health training/education needs assessment, and to develop new distance learning rural health training/educational modules based on needs assessment
Workforce Recruitment and Retention	To develop and focus future efforts on identifying and developing healthcare professionals at various stages (i.e., undergraduate, graduate, and professional training programs). Initiatives may include funding through grants for students who agree to provide care within these communities
Building Collaborations	To expand partnerships with VA program offices, federally funded offices (i.e., Department of Defense, Agency for Healthcare Research and Quality, Centers for Medicaid and Medicare Services)

Source: Department of Veterans Affairs, Veterans Health Administration, Office of Rural Health. (2011) Strategic plan: 2012–2014

as urban (accounting for 5,177,944; 62.1% of veteran enrollees); all other areas are classified as rural (3,031,357; 36.4%), excluding areas with a population density of seven or less per square mile, which are classified as highly rural (125,588; 1.5%; West et al., 2010).

The coding system was designed to determine whether the standards for travel time are being met (i.e., appropriate allocation of travel reimbursement) and to assess for regional differences in healthcare delivery. Assessing for demographic variations allows agencies to determine the type of resources necessary for allocation within a specific geographic region. Specifically, these resources can include primary care, emergency services, increased mental healthcare providers within the Veterans Affairs (VA), need for outsourcing, obstetrics and gynecology, etc. Based on the previously reported incidence of Veteran enrollees within R/HR populated areas, approximately 37.9% face challenges to receiving appropriate healthcare due to lack of available services, which is further addressed later in this chapter (Veterans Healthcare Administration [VHA], 2003). The eligibility criteria for VA services are limited to individuals who were active duty service members, current or former reservists, or the National Guard who were either called into active duty or completed the full period of their active duty service (Brown et al., 2015). For the purposes of this chapter, we define "veteran" as individuals who actively served in the U.S. Armed Forces, military reserves, or National Guard.

Rural Americans account for only 20% of the population; yet, approximately half of all military recruits come from small towns and rural areas (Alfers & Heady, 2014; Department of Defense, 2013). Nonetheless, the demographic data on military recruits and veterans is never stable which can be explained by an aging population (e.g., we have fewer WWII and Vietnam veterans), rise in U.S. military conflicts (i.e., Post-9/11: OND, OIF, and OEF), and physical and mental health conditions (e.g., increased suicide rates). The U.S. Census Bureau (2014) estimates approximately 12% of rural veterans are identified as racial minorities and 7% (1.6 million) are female. In comparison to their urban counterpart, veterans residing in rural areas sustain higher ratings and percentages of service-connected disabilities, generally endure more than one disability, have a lower educational attainment and higher unemployment rates, and require traveling lengthy distances to receive services provided through the VA. Aside from physical disability and mental health statistics, which are discussed in the proceeding sections, specific demographic information is necessary for the vocational rehabilitation counselor (VRC) and mental health clinician to successfully assist their clients. Accordingly, we provide the specific makeup of the veteran population residing in rural and urban areas outlined in Table 8.3.

Mental Health

Seeking to obtain generalizable statistics surrounding psychiatric disorders among the veteran population tends to be challenging. This is particularly due to the differences between geographical regions, fewer number of veterans enrolling into the VHA as a result of barriers to treatment (i.e., long wait times, geographical distance, and being unaware of eligibility for VHA services), time of service (Vietnam, Gulf War, OEF/OIF, etc.), number of veterans choosing not to self-report having a mental health condition for fear of stigma, and reduced employment opportunities within the U.S. federal government. Yet despite these challenges, there have been consistent findings for the prevalence of the most commonly occurring mental health disorders among these populations.

Returning veterans and active military are meeting the diagnostic criteria for various mental health disorders with PTSD accounting for 37%, which has increased sevenfold Post-9/11 (Zeber, Noel, Pugh, Copeland, & Parchman, 2010). However, while PTSD is the most notable mental health condition, which can be accompanied by depression and substance abuse disorder (SUD), the prevalence of other psychiatric disorders is increasing. For instance, the prevalence of depression alone has risen from 2.3% to 17.4%, while substance abuse disorder (SUD) increased from a staggering 6.4% to 36.9% (Milanak, Gros, Magruder, Brawman-Mintzer, & Frueh, 2013). However, for individuals who served Post-9/11, the mental health diagnosis for depression is an alarming 45%, and anxiety disorder not including PTSD is at 43% (Pickett et al., 2015). Additionally, the incidence rate of women veterans experiencing

Table 8.3 Demographic Characteristics of Rural and Urban Veterans

Characteristic		
	Rural veterans (%)	*Urban veterans* (%)
Age	18–34 years (6.4) 35–54 years (25.7) 55–64 years (26.9) 65–74 years (21.6) 75 years or older (19.3)	18–34 years (8.7) 35–54 years (25.5) 55–64 years (23.3) 65–74 years (18.9) 75 years or older (23.4)
	Rural veterans (*male* %; *female* %)	*Urban veterans* (*male* %; *female* %)
Age distribution by gender	18–34 years (5.6; 19.1) 35–54 years (23.9; 50.5) 55–64 years (27.6; 16.9) 65–74 years (22.7; 6.5) 75 years or older (31; 7)	18–34 years (7.5; 22.6) 35–54 years (23.9; 45.8) 55–64 years (24.2; 14.7) 65–74 years (20.0; 6.3) 75 years or older (24.4; 10.6)
	Rural veterans (%)	*Urban veterans* (%)
Race/ethnicity	White (91) Black (5.7) Hispanic (2.7) Asian (0.5) American Indian/Alaska Native (1) Pacific Islander (0.1) Some other race (0.5) Two or more races (1.3)	White (81.6) Black (13.2) Hispanic (6.4) Asian (1.5) American Indian/Alaska Native (0.6) Native Hawaiian/Pacific Islander (0.2) Some other race (1.4) Two or more races (1.6)
	Rural veterans (%)	*Urban veterans* (%)
Education	< HS graduate (9.5) HS grad (33.9) Some college or assoc. degree (35) Bachelor's degree or higher (21.6)	< HS graduate (7.5) HS grad (28.2) Some college (36.6) Bachelor's degree or higher (27.7)
	Rural veterans (%)	*Urban veterans* (%)
Employment	Employed (66.5) Unemployed (6.4) Not in labor force (27.1)	Employed (68.6) Unemployed (7.9) Not in labor force (23.5)
	Rural veterans (%)	*Urban veterans* (%)
Disability status	No disability (73.1) More than one disability (26.9)	No disability (75) More than one disability (25)
	Rural veterans (%)	*Non-rural veterans* (%)
Poverty status	Below poverty level (6.2) At or above poverty (93.8)	Below poverty level (6.9) At or above poverty (93.1)
	Rural veterans (%)	*Non-rural veterans* (%)
Service-connected disability	0% (6) 10% or 20% (35.9) 30% or 40% (15.7) 50% or 60% (10.2) 70% or higher (22.6) Rating not reported (9.7)	0% (7.3) 10% or 20% (37.5) 30% or 40% (16.4) 50% or 60% (9.5) 70% or higher (19.6) Rating not reported (9.7)

Source: U.S. Census Bureau, American Community Survey (2014)

the abovementioned psychiatric disorders is increasing. For instance, 52% of women veterans indicate the need for mental healthcare often as a result of PTSD, military sexual trauma, and depression (VA, 2015b). Unfortunately, many women veterans are hesitant to healthcare services due to concerns over the perceived stigma of counseling, side effects of medicine, the possibility over it affecting the relationship with the family/spouse, and spirituality and/or religion (VA, 2015b).

As previously discussed, the National Guard and reservists contribute to a significant percentage of the veteran population, and they alone screen positive for mental health disorders at a rate of 42.4% (Milliken, Auchterlonie, & Hoge, 2007). Interestingly, some researchers have sought to determine whether differences in mental health disorders among rural and non-rural National Guard, Reservists, and veterans exist. Among 617 veteran participants in a study conducted by Bennett, Crabtree, Schaffer, and Britt (2011), higher proportions of those who resided rural areas (26%) in comparison to urban hubs (18%) met the diagnostic criteria for PTSD. Additionally, higher rates of self-reported traumatic experiences were reported by 63% of rural National Guard and reservists in comparison to their urban counterpart. Additionally, both groups had similar rates for depression and suicidal ideation (approximately 10% and 18%, respectively). Similar to the aforementioned findings, the overall rates of veterans who reside in rural communities tend to be similar to that of those who live in urban populated areas. As demonstrated in Table 8.4, the proportions of psychiatric disorders generally remain the same regardless of geographical variances; nonetheless, treatment opportunities differ greatly for individuals residing in rural communities.

Table 8.4 Prevalence of Six Psychiatric Disorders in Rural and Urban Veteran Populations

	Rural ($N = 148{,}989$)		Urban ($N = 421{,}523$)	
Disorder	*N*	%	*N*	%
Depression	18,300	12.3	57,239	13.6
Anxiety, excluding posttraumatic stress disorder (PTSD)	12,793	8.6	36,704	8.7
PTSD	9,139	6.1	28,856	6.8
Alcohol dependence	7,017	4.7	28,985	6.9
Schizophrenia	3,481	2.3	17,421	4.1
Bipolar disorder	2,445	1.6	11,345	2.7
Total number of Veterans with disorders	31,465	21.1	96,887	23.0

Note. Adapted from *Rural and Urban Disparities in Health-Related Quality of Life Among Veterans with Psychiatric Disorders, 57*, p. 853. Copyright 2006 by Psychiatric Services

Medical Conditions

Since September 11, 2001, more than 2.5 million veterans served in Operation Iraqi Freedom, Operation Enduring Freedom, and Operation New Dawn. Unfortunately, approximately 31,000 service members were wounded in action from these recent conflicts, while over 3000 returned home from Iraq and Afghanistan with severe wounds, illnesses, and/or disabilities, which have included amputations, serious burns, spinal cord injuries, blindness, and traumatic brain injuries (President's Commission on Care for America's Returning Wounded Warriors, 2007). Although it is difficult to determine the overall incidence rate of veterans with a disability, the U.S. Census Bureau estimates 1.5 million (31%) of rural veterans have a disability with over 891,000 directly attributed to their military service (U.S. Census Bureau, 2017). Details outlining the top rated medical conditions in rural and urban veteran populations can be found in Table 8.5.

In addition to the most commonly occurring medical conditions found among all rural veterans, there is a greater likelihood than their urban counterpart to have more than one disability with a rating of 50% (National Center for Veterans Analysis and Statistics, 2012). Notably, however, female veterans residing in rural areas contribute to the medical conditions outlined in Table 8.5 while having additional and specific healthcare issues unmet (National Center for Veterans Analysis and Statistics, 2012). These include but are not limited to (a) heart disease, (b) diabetes, (c) hypertension, (d) high-risk pregnancies, (e) musculoskeletal pain, and (f) chronic pain (National Organization of State Offices of Rural Health [NOSORH], 2014). Despite continuous effort to improve overall access of healthcare services to veterans, optimize the use of available and emerging health information technology, and enhance availability of education and training of VA services, the rural veteran population continues to struggle with both mental health issues and medical conditions, which often affect overall quality of life. Lastly, eligible veterans can

Table 8.5 Prevalence of Top Rated Medical Conditions in Rural and Urban Veteran Populations

Disease Categories	Rural, *N* = 148,989 (%)	Urban, *N* = 421, 523 (%)
Hematological/oncological disorders (i.e., anemia, skin cancer)	11.8	11.2
Cardiopulmonary disorders (i.e., hypertension, chronic obstructive pulmonary disease, atrial fibrillation, angina, etc.)	53.5	49.1
Musculoskeletal disorders (i.e., osteoarthritis, low back pain, other arthritis conditions, gout and other joint complaints, rheumatoid arthritis, and hip problems)	29.8	24.3
Gastrointestinal disorders (i.e., chronic liver disease, inflammatory bowel disease, etc.)	9.9	8.3
Urological disorders (i.e., urinary tract infection, prostatitis, and benign prostatic hypertrophy)	19.3	16.9
Endocrine disorders (i.e., diabetes and thyroid)	20.5	20.0
Other medical conditions (i.e., cataracts and epilepsy)	15.1	15.3

Note. Adapted from *Rural-Urban Disparities in Health-Related Quality of Life Within Disease Categories of Veterans, 22*, p. 208. Copyright 2006 by the National Rural Health Association

receive an array of benefits that consist of healthcare, disability compensation, pension, education and training, and vocational rehabilitation services. Details outlining each of the benefits can be found in Table 8.6.

Transitional Difficulties Post Military Discharge

For the general public, the concern over job security and healthcare is generally nonexistent until postadolescence. At working age, employment opportunities are afforded based on educational attainment, work experience, and networks (i.e., family and friends), while healthcare is provided through a caregiver's insurance. Subsequently, once a person enters the military, employment and healthcare are of insignificant concern as both are concurrently met, although the amount of pay is often debatable. However, once discharged from the armed forces, available resources for job opportunities and access to healthcare become problematic, even more so for individuals living within rural communities. The lack of both job security and overall healthcare needs often results in frustration, anxiety, depression, and maladaptive behaviors (e.g., substance abuse) by veterans, active military, and National Guard. A lower percentage of rural veterans employed may be due to decreased job opportunities as a result of fewer businesses in comparison to urban society. Additionally, when combining the employment challenges with difficulties toward identifying transferable skills based on military experience, microaggressions, and the acquisition of a service-connected disability, the transitional/reintegration process into civilian life can be strenuous.

Veteran Benefits

The US Department of Veterans Affairs (VA) offers a variety of services/benefits to uniformed service members (i.e., National Guard or active military), veterans with or without a service-connected disability (or disabilities), the spouse, child, and/or parent of a deceased or disabled veteran (U.S. Department of Veterans Affairs, 2015c). However, despite the vast number of programs provided through the VA, there have been controversial concerns raised by the media and veterans as a result of the following: (a) the restriction of telehealth services due to limited broadband coverage, (b) inadequate primary care and mental health programs, (c) long wait times before being seen by a primary healthcare

Table 8.6 Veteran Benefits

Benefits	Description of Services Provided
Healthcare	Treatment related to military sexual trauma; readjustment counseling; medical evaluation for mental health diagnoses, community-based residential care; hospital, outpatient medical, dental, pharmacy, and prosthetic services; homeless Veteran programs; substance abuse programs; and specialized care for women Veterans
Disability compensation	Tax-free service-connected disability compensation paid to Veterans for a disability (or disabilities)
Pension	Wartime Veterans aged 65 years or older with limited or no income are eligible for a tax-free pension benefit
Education and training	VA pays benefits through the Post-9/11 GI Bill, Montgomery GI Bill, Montgomery GI Bill-Selected Reserve, and Reserve Educational Assistance Program to eligible Veterans and active duty service members pursuing education or a training program
VetSuccess	Veterans with a service-connected disability are provided assistance in preparing for, obtaining, and maintaining suitable employment

Source: U.S. Department of Veterans Affairs (2012)

physician and/or a mental health counselor, (d) lack of available transportation, and (e) increased driving distance. And although wait time has been significantly reduced, many continuously experience extended waiting periods exceeding one month. Therefore, the amalgamation of distance and lengthy waiting periods leads to a surmounting number of veterans, National Guard, and service members deficient of appropriate healthcare needs. To illustrate this case in point, a qualitative study to assess for perceived barriers toward healthcare access revealed 33% of veterans reported travel distance as the greatest hindrance, followed by the lack of specialty care at 15–20% (Goins, Williams, Carter, Spencer, & Solovieva, 2005). As previously noted, approximately 1.3 million military service members and dependents have been reported to be geographically remote from behavioral healthcare yet; half of the Veterans Health Administration enrollees live within 1 h of primary care, while 70% must travel more than 2 h for acute care or 4 h for tertiary care (Brown et al., 2015; West et al., 2010).

It is important to note, while approximately 30% of veterans (i.e., ages 18–34) have served in OIF, OEF, and OND, the median age of rural veterans ranges from 55 to 64, and 50.5% aged 35–54 are women veterans (NOSORH, 2014). As a result, overall access to healthcare services not only affects individuals who have been recently discharged but also an aging veteran population. Likewise, females account for 50.5% of rural veterans aged 35–54 and encounter equivalent barriers to the male veteran population but are often burdened with childcare issues, inconvenient clinic operating hours, and lack of access to immunizations/vaccines (NOSORH, 2014).

Barriers Toward Receiving Educational Benefits

Similar to clients with a disability seeking educational assistance in state Vocational Rehabilitation agencies to enhance employment opportunities and outcomes, veterans with and without disabilities often enter postsecondary education or trade schools for the following reasons: (a) military experience generally does not translate well into the job market; (b) service-connected disability may interfere with performing the essential functions of the job for which the veteran has been trained; and (c) receiving a monthly housing allowance which can exceed $1700. However, the latter is determined based on number of hours enrolled (i.e., full time, part time, etc.), whether the program is strictly online, and the state in which the veteran resides.

When veterans reside in rural communities, attending an institution of higher education or a trade school can pose significant challenges due to geographical distance. When residing 60 or more miles away from the nearest institution of higher education or trade school, many resort to relocating and/or enrolling into a strictly online program. However, the VA reduces the educational benefits received when enrolled exclusively online but does provide a "rural benefit" one-time payment of $500 to veterans who relocate at least 500 miles to attend an educational institution (U.S. Department of Veterans Affairs, 2012). Nevertheless, the "rural benefit" is inadequate when considering the overall cost of relocating. Thus, many resort to solely online programs which reduce the amount of their monthly income.

Summary

Veterans have historically experienced an array of hardships post military discharge, and despite legislative efforts, access toward veteran benefits remains challenging. Currently, of veterans enrolled into the Veterans Health Administration, approximately three million rural veterans (66%) do not use a VA healthcare system despite the vast number of veterans meeting the diagnostic criteria for a psychiatric disorder, mental health condition, or both. For veterans who reside in rural communities, receiving the necessary resources toward overcoming the aforementioned hardships is primarily the result of geographical distance, long waiting times, lack of transportation, restricted telehealth services, and inadequate healthcare. Subsequently, when veterans and their dependents are unable to utilize the VA benefits specifically designed to aid in transition (i.e., educational benefits) and improve health, hardships carryover to the nuclear family as demonstrated by the over 30,000 divorces since 2010. Moreover, challenges toward obtaining benefits that are specifically designed to assist veterans toward transition are often a moot point for those residing in rural areas which ultimately affect quality of life (QOL).

Discussion Scenario 1

Despite continuous efforts by the Department of Veterans Affairs to reduce geographic challenges faced by servicepersons and veterans seeking specialized care (i.e., orthopedic specialist), many require traveling great distances (e.g., distance greater than 40 miles from a VA facility) to receive appropriate medical treatment or encounter relatively long wait periods even when outsourced. And although wait time has been significantly reduced, many continuously experience vast waiting periods exceeding one month. Therefore, the amalgamation of distance and lengthy waiting periods leads to a surmounting number of veterans, National Guard, and service members deficient of appropriate healthcare needs. To illustrate this case in point, a qualitative study to assess for perceived barriers toward healthcare access revealed 33% of veterans reported travel distance as the greatest hindrance to receiving services (Goins, Williams, Carter, Spencer, & Solovieva, 2005):

1. You are a vocational rehabilitation counselor employed within the VHA located in an urban hub. The area in which you provide vocational rehabilitation services includes the town in which the VHA resides and three towns outside which are designated as "rural." How would you evenly plan out your cases to ensure each client receives the appropriate level of assistance based on their individual need? How would you safeguard against extended wait times, long driving distances, and/or lack transportation to and from appointments?
2. What are possible solutions to this issue?
3. What is the role of e-counseling?

Discussion Scenario 2

Aside from the general barriers affecting veterans from seeking and obtaining VHA services, one study found the most common reason potentially eligible rural veterans did not use VA care was that they were unaware of their eligibility (Wittrock, Ono, Stewart, Reisinger, & Charlton, 2015). These findings pose great concern as rural veterans tend to have more physical and mental health comorbidities and are in greater need for VA services than non-rural veterans (Weeks et al., 2004):

1. As a rehabilitation counselor, how would you provide marketing services to rural communities and ensure veterans are aware of the available resources and services provided through your agency?
2. What is the responsibility of the military discharge planners with regard to this issue?
3. Besides the agency, what are additional sources of providing information to veterans in rural communities?

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Marginalized Racial and Ethnic Adults with Disabilities in Rural Communities: The Role of Cultural Competence and Social Justice

Debra A. Harley and Brenda Cartwright

Overview

Historically marginalized groups (hereafter, marginalized groups) – Hispanic/Latino, Black/African American, and American Indian – make up about a quarter of the people living in rural America. While rural Asian Americans/Pacific Islanders are the exception and are not geographically concentrated on the mainland, over half reside in Hawaii, California, New York, Oregon, and Wisconsin; other marginalized groups, particularly those who are poor, are geographically concentrated in different regions:

- Seventy percent of African Americans reside in rural Southern states of Mississippi, Georgia, North Carolina, Louisiana, Alabama, and South Carolina.
- Seventy-three percent of Hispanic/Latino Americans reside in rural Southwestern states of Texas, New Mexico, California, Arizona, and Colorado.
- Fifty-seven percent American Indian/Alaskan Natives reside in rural Western states of Arizona, New Mexico, Oklahoma, South Dakota, and Montana (Probst et al., 2002, p. 2).

As more marginalized groups, particularly Hispanic/Latino Americans, have moved out of large urban areas into rural communities and smaller cities, rural areas continue to become even more diverse. The immigration rates of Hispanic/Latino Americans have increased their numbers in rural areas, in part because of the shift from seasonal workers who came to the United States to work on farms and left after harvest time to immigrants who remain. Subsequently, rural marginalized groups lag behind rural European Americans and urban groups on many crucial economic, health, educational, and social measures (Bahls, 2011; Bennett, Bellinger, & Probst, 2010; Probst, Bellinger, Walsemann, Hardin, & Glover, 2011). The diversification of rural areas further emphasizes the need to understand differing cultural belief systems and the importance of cultural competency of rehabilitation counselors and other human/social service providers.

Studies over the past four to five decades show minimal progress for marginalized groups as measured by changes in occupation, income, and poverty rates (Leung & Wright, 1993; Probst et al., 2002; Swanson, 1996). Individually and collectively, marginalized groups in rural areas have disproportionately higher poverty rates.

D.A. Harley (✉)
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: dharl00@email.uky.edu

B. Cartwright
Department of Rehabilitation Counseling, C024 C Anderson Center, Winston Salem State University, Winston Salem, NC, USA

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Over two decades ago, Leung and Wright (1993) reported that marginalized group members with disabilities "are more at-risk, have fewer personal and family resources, have less knowledge and understanding of externally available resources, and fare less well socioeconomically than do marginalized groups without disabilities" (p. 17). More recently, in a study of self-rated health status among adults with disabilities, Blacks/African Americans and Hispanic/Latino Americans were more likely to report fair to poor health status compared to European American adults (Mead et al., 2008). In addition, the prevalence of disability was reported to be higher among Blacks/African Americans, American Indians, and Alaskan Natives with persistent disparities in their quality of healthcare (Centers for Disease Control and Prevention [CDC], 2006; Fiscella & Sanders, 2016). Asian Americans/Pacific Islanders with disabilities have not been studied as extensively as other marginalized groups.

A further common complication among members of rural marginalized groups is that they are more likely to have lower hourly wages and higher unemployment and subsequently face disparities in the availability of quality of care and access to healthcare resources, services, and providers, especially among Hispanic/Latino Americans and poor people (Bahls, 2011; National Advisory Committee on Rural Health and Human Services [NACRHHS], 2004; The 2010 National Healthcare Quality and Disparities Reports) (see Table 9.1). Although implementation of the Affordable Care Act (ACA) has helped to reduce the gap of uninsured individuals, marginalized groups still remain uninsured at a higher rate than European Americans (Agency for Healthcare Research and Quality, 2014). Disparities continue to persist (U.S. Census Bureau, 2006) and are predicted to continue into the foreseeable future (CDC, 2006; U.S. Census Bureau, 2013; U.S. Census Bureau, 2014).

Table 9.1 Racial and ethnic minorities' healthcare disparities

Quality: Blacks and American Indians and Alaskan Natives received worse care than Whites for about 40% of measures. Asians received worse care than European Americans for about 20% of measures. Hispanics received worse care than non-Hispanic Whites for about 60% of core measures. Poor people received worse care than high-income people for about 80% of core measures.
Access: Blacks had worse access to care than Whites for one third of core measures. Asians, American Indians, and Alaskan Natives had worse access to care than Whites for one of five core measures. Hispanics had worse access to care than non-Hispanic Whites for five of six core measures. Poor people had worse access to care than high-income people for all six core measures.
Outlook: Fewer than 20% of disparities faced by Blacks, American Indians, Alaskan Natives, Hispanics, and poor people showed evidence of narrowing. The Asian-White gap was narrowing for about 30% of core measures, the largest proportion of any group, but most disparities were not changing.

Adapted from The 2010 National Healthcare Quality and Disparities Reports

Rural marginalized group members with disabilities are considered to have a triple marginal group status – racially/ethnically, disability, and geographically. In addition, these groups have higher rates of disability and more health disparities than their European American counterparts. There is consensus in studies that examined the provision of VR services to individuals with disabilities in conjunction with their marginal racial background that some disparity exists based on racial status of VR applicants, services provided, closure types, and employment outcome status (Atkins & Wright, 1980; Capella, 2002; da Silva Cardoso, Romero, Chan, Dutta, & Rahimi, 2007; Jones, 2008; Kim-Rupnow, Park & Starbuck, 2005; Martin, 2010; Rosenthal, Ferrin, Wilson, & Frain, 2005; Wheaton, & Hertzfeld, 2002; Wilkerson, & Penn, 1938; Wilson, 2004; Wilson, Harley, & Alston, 2001; Wilson, Turner, & Jackson, 2002). Furthermore, agreement in the literature is that marginalized groups have been underserved in the public vocational rehabilitation service system for decades (Chan, Wong, Rosenthal, Kundu, & Dutta, 2005; Kim-Rupnow, et al.; Mwachofi, 2008).

Learning Objectives

By the end of the chapter, the reader should be able to:

1. Identify disability, health, and healthcare disparities for marginalized groups.
2. Distinguish areas of concern between rural and urban marginalized groups.
3. Understand why cultural competence is important, particularly in rural areas.
4. Incorporate multicultural and social justice competencies into professional practice, adopting culturally sensitive practices and interventions to address the needs of rural clients from marginalized groups to enhance employment outcomes.

Introduction

"While rural Americans are predominately White, there is significant diversity in many rural areas" (NACRHHS, 2004, p. 10). Data from the 2010 Census of Population and Housing report that approximately one quarter of the people living in rural America are members of marginalized groups. Hispanic/Latino Americans make up about 9.3% of rural populations, followed by Black/African Americans at 8.2% and American Indians at 1.5%. More than half of the residents of the rural population live in counties with marginalized populations that will become majorities by mid-century (U.S. Census, 2013).

Rural areas have been plagued by higher rates of chronic illnesses and limitations in activities of daily living. The rate of disability varies among marginalized adults. In 2015, Blacks/African Americans had a higher prevalence of disability than Hispanic/Latino Americans and Asian Americans (Bureau of Labor Statistics, 2016). Blacks/African Americans have higher than average rates of disabilities, in part, because of the types of occupations they have. Marginalized groups are concentrated in jobs with high physical demands. Some rural areas have a higher percentage of farming and manufacturing jobs, while others might have more recreation and tourism jobs, subsequent to the availability of lakes, mountains, and forests. Farming remains a major industry in rural areas and has one of the highest levels of occupational stress, both physical and economic (Glasscock, Rasmussen, Carstensen, & Hansen, 2006). Farming is a hazardous profession with high rates of job-related illnesses, injuries, and disabilities from machinery, livestock, tools, and work surfaces and exposure to long hours in the sun, deafening noise, toxic chemicals, gases, and fuels, and dust from animal feeds and hay. In addition, farmers are exposed to zoonotic and respiratory illnesses because they work in animal enclosures, silos, and manure pits (National Institute for Occupational Safety and Health, 2004; Smith, 2011). Marginalized farmers experience higher incidences of injury than European American farmers. These high injury rates are exacerbated by the difficulty to access services in rural areas.

Attitudes Toward Disability

Meanings of health, illness, and disability vary greatly across cultures and time. This is particularly significant since beliefs about the cause of illness appear to be important determinants of health-related behaviors, including strategies for self-care, health seeking, and decision-making about what treatments to use and what outcomes to expect (Bryan, 2007; Cartwright, 2010; Groce & Zola, n.d.). Those who share a culture have their own explanations for illness and disability, which may differ from or include biomedical explanations. In fact research in health psychology, anthropology, and sociology over the last several decades indicate that:

> individuals subscribing to the Western biomedical system perceive health and illness from a scientific point of view focused on what can be observed and measured. Persons holding this view tend to attribute illness to natural factors, including poor diet, smoking, alcohol use, lack of exercise, stress, weight, and heredity. On the other hand, individuals subscribing to Eastern medical systems hold a holistic view about health and illness that considers mind, body, and spirit as an integral whole. In addition to natural causes, many of these individuals tend to attribute illness to supernatural factors, including God's punishment, destiny and karma, as

> well as sinful thoughts, witchcraft, the Evil Eye, and voodoo. (Cartwright, Zhang, & Jin, 2014, p. 969)

Many marginalized populations do not define or address disability and chronic illness in the same manner as European Americans or "mainstream" American culture (Bennett, Zhang, & Tarnow, 2000; Groce & Zola, n.d.; Sue & Sue, 2015). In some languages, for example, Spanish, the word disability does not exist. Attitudes toward disability may vary depending on the type of disability (e.g., physical vs. psychological). The extent to which a group engages in traditional and indigenous practices also influences their views and attitudes toward disability (Burnhill, Park, & Yeh, 2009; Harley, 2005). Indigenous practices or healing refers to culturally bound explanations of behaviors and physical conditions and the cultural-specific ways of dealing with human problems and distress (Burnhill et al.; Yeh, Hunter, Maden-Bahel, Chiang & Arora, 2004). From the beginning of time, cultures have developed strategies (i.e., worldview and prevailing philosophy of life) of dealing with psychological distress, behavioral aberration, and physical ailments. Generational differences also may dictate attitudes and perceptions about disability. For example, older adults may hold closer to traditional cultural beliefs and practices than younger adults and adolescents. Other dimensions such as religion, geography, and gender contribute to attitudes, beliefs, and perceptions about disability and help seeking.

Considering the intra- and intercultural diversity of marginalized groups, the attitudes and perceptions toward disability that are presented here is to provide the reader with an overview rather than a prescriptive view. In light of the increasing diversity of the United States, Balcazar (2010) contends that the topics of race, culture, and disability have rarely been examined together. First and foremost, it is important to recognize that there is no one culture that fits any group of people; rather, there are numerous cultures associated with any ethnic group (Bryan, 2007). For example, a Latino reared in rural Alabama will have some similarities to a Latino reared in Los Angeles; however, the two will have many different experiences, which will mean their cultural backgrounds will be different. Bryan suggests there may be more cultural similarities between a Latino reared in rural Alabama and a Caucasian reared in rural Alabama than between a Latino Los Angeles native and the Latino Alabama native. A point of caution is that as human service professionals, counselors must avoid falling into the trap of generalizing specific cultural characteristics to all members of that group. Bearing that in mind, this section presents commonly held attitudes and perceptions toward disability that may be shared among and between marginalized groups.

Attitudes about disability also differ based on the type of disability. For example, society in general has negative attitudes about mental illness and tends to stigmatize people with such diagnoses. The *Attitudes Toward Mental Illness: Results from the Behavioral Risk Factor Surveillance System* found that most adults agreed that treatment can help people living with mental illness lead "normal" lives, yet respondents believed that people are generally not caring and sympathetic to people with mental illness (Centers for Disease Control and Prevention et al., 2012). In studies that specifically examined marginalized group members' attitudes toward mental illness, African American men and women were not very open to acknowledging psychological problems, were very concerned about stigma associated with mental illness, and were somewhat open to seeking mental health services, but they prefer religious coping. Overall, significant gender and age differences were evident in attitudes and preferred coping, with young women having more positive attitudes and openness to seeking help than younger men. Middle-aged and older men and women had a higher propensity for seeking help overall compared to other groups (Ward, Wiltshire, Detry, & Brown, 2013). While African American adults have similar rates of depression as European Americans, they are significantly less likely to seek help. Conner et al. (2010) suggested that cultural differences in the way depression symptoms are manifested, defined, interpreted, and labeled, in part, explain some of the racial differences in help-seeking behaviors.

Asian Americans as an ethnic group are reported to underutilize mental health services. The reason for this is the commonly held belief that Asian Americans' cultural values conflict with the counseling process, when often the plausible explanation for early termination is the inadequacy of the service provided. In an earlier study, Atkinson and Gim (1989) examined the relationship between cultural identity and attitudes toward mental health of Asian American (i.e., Chinese, Japanese, and Korean) college students and found, regardless of ethnicity and gender, most acculturated students were (a) most likely to recognize personal need for professional, psychological help, (b) most tolerant of the stigma associated with psychological help, and (c) most open to discussing their problems with a psychologist. Forty-three percent of Asian American women in a recent study reported that they either suffered from current moderate to severe depression symptoms or a lifetime history of suicidal ideation or suicide attempt. Mental health risk groups were created based on participants' current depression symptoms and history of suicide behaviors: Group 1, low risk; Group 2, medium risk; and Group 3, high risk. Although the high-risk group demonstrated statistically significant higher mental health utilization compared to the low- and medium-risk groups, more than 60% of the high-risk group did not access any mental healthcare, and more than 80% did not receive minimally adequate care. Three underutilization factors were identified: (1) Asian family contributions to mental health stigma, (2) Asian community contributions to mental health stigma, and (3) a mismatch between cultural needs and available services (Augsberger, Yeung, Dougher, & Hahm, 2015).

While some Hispanic/Latino Americans have a negative attitude toward mental healthcare, and lower rates of access than non-Hispanic/Latino European Americans, research is sparse examining this issue or supporting this view. According to Shim, Compton, Rust, Druss, and Kaslow (2009), Hispanic/Latino Americans may have more positive attitudes than non-Hispanic European Americans and have treatment barriers, not because of attitudes but because of socioeconomic factors, language barriers, and other structural barriers to care. In addition to language barriers, Hispanic/Latino Americans have cultural values that create barriers. Moreover, bilingual clients are evaluated differently when evaluated in English versus Spanish, and Hispanic/Latino Americans are more frequently undertreated than European Americans (Dingfelder, 2005). Focusing on the misconceptions and personal beliefs associated with depression, Jang, Chirboga, Herrera, Tyson, and Schonfeld (2009) explored predictors of attitudes toward mental health services of older Hispanic/Latino adults and found that negative attitudes toward mental health services were predicted by advanced age, belief that having depression would make family members disappointed, and belief that counseling brings too many bad feelings such as anger and sadness. Clearly, generational differences exist with regard to attitudes and perceptions about mental health among Hispanic/Latino populations.

The attitudes of Hispanic/Latino populations toward mental illness might also be influenced by *culture-bound syndromes* (Diagnostic and Statistical Manual, DSM, 2013). Culture-bound syndrome is "a cluster or group of co-occurring, relatively invariant symptoms found in a specific cultural group, community, or context" (DSM, 2013, p. 14). The *DSM* names three culture-bound syndromes sometimes found in Hispanic/Latino populations. The first is *ataque de nervios* – intense emotional upset, often with shouting, screaming, and crying; feelings of heat, verbal, or physical aggression; sometimes dissociative experiences, seizures, or fainting; and sometimes suicidal gestures. This is often a response to a stressful event related to family. The second syndrome is *nervios* – a state of vulnerability to stress, often with multiple somatic and emotional symptoms. The final syndrome is *susto* – varying symptoms that are attributed to a frightening event that causes the soul to leave the body. Yet, other Hispanic/Latino Americans might function under the belief of *mal de ojo* (evil eye), in which sickness is believed as sent or caused by others. It is important to note several disadvantages of the term culture-bound syndrome are that it (a) "ignores the fact that clinically important cultural differences often involves explanations or experience of distress, rather than culturally distinctive configuration or symptoms" and (b) "overemphasizes the local particularity and limited distribution of cultural concepts of distress" (DSM, p. 758).

The role of culture not only influences how we view disability in general but how we view people with disabilities. Pfeiffer et al. (2003) argued that beyond looking at a specific person with a disability, in the helping professions (e.g., rehabilitation, nursing, social work, psychology), people with disabilities and the disability cannot be separated because the concept of a person with a disability embodies the phenomenon of disability. In some ways, this argument is the opposite of the pro-person-first language that promotes the identification of the person, not the disability (e.g., person who is deaf). Yet, deaf culture promotes identification of their disability as part of their identity, thereby referring to themselves as deaf people. Deaf culture's conception of disability is more in line with that of Pfeiffer (see Chap. 15 for discussion of deafness).

Palmer, Redinuis, and Tervo (2000) examined attitudes toward disabilities among rural and urban college students and found they both had positive attitudes. However, rural students exhibited more negative attitudes toward the personality of people with disabilities (e.g., factors labeled "derogatory personality stereotypes" and "behavioral misconceptions"). A more recent study examining implicit and explicit attitudes toward persons with disabilities among Chinese college students indicated that students tended to hold negative attitudes implicitly and positive attitudes explicitly toward persons with disabilities. In particular, students from rural areas exhibited more negative implicit attitudes than those from urban areas; males demonstrated more negative explicit attitudes than females (Chen, Ma, & Zhang, 2011). Another recent study investigating two groups (i.e., those who viewed Paralympic-level ID sport footage and information and those who viewed Olympic footage and information) and determining whether stimuli depicting people with intellectual disabilities (ID) performing at Paralympic level of competition was effective in changing attitudes toward ID. The results suggested that implicit attitudes significantly changed in a positive direction for both groups. The findings provide evidence that both Paralympic (ID) and Olympic media coverage may have at least a short-term effect on attitudes toward people with disabilities (Ferrara, Burns, & Mills, 2015).

The cultural views of marginalized groups, as well as their rural culture, can impact how they view helping professionals. In a study of attitudes of persons with physical disabilities and Black Americans toward counseling professionals, Hansen and Bryant (1991) found that both groups may not seek professional counseling because of the perception that the counselor is just one more authority figure who makes their decisions and controls their lives. Considering that recruitment and participation in clinical trials by minorities, particularly African Americans and rural underserved populations, were low, a cross-sectional design was used to survey adults residing in Maryland, including urban Baltimore City, the rural regions of Western Maryland, and the Eastern Shore. Findings revealed that Black and middle-income respondents were significantly less likely to actually participate in clinical trials, whereas respondents who received information about clinical trials from their healthcare provider, who were knowledgeable about clinical trials, and those who had the time commitment were significantly more likely to participate in clinical trials. These results suggest continued gaps in efforts to recruit racial/ethnic minorities and residents of rural regions into clinical trials (Baquet, Commiskey, Mullins, & Mishra, 2006).

Another study examined the perceptions, attitudes, and experiences of African American male students with school counselors and their school counseling services. Despite being Black, male, poor, and enrolled in special education, most planned to pursue postsecondary education after high school graduation. Participants had both positive and negative perceptions and comfort levels with school counselors. The findings also indicated that the students had many expectations and experiences with their school counselors, but they were oftentimes not fulfilled. It is interesting that the participants did not perceive career issues as one of the roles of school counselors. Analysis of results revealed that those who did seek the assistance of school counselors seemed to have benefited; however, such assistance tended to focus on scheduling and academic planning. Similar to what was found in the research literature on African American males and counseling, the African American male participants illustrated comfort-level issues with their school counselor. Some of the comfort-level issues were related to past school counselor experiences, family-school boundaries, school counselor time availability, and school counselor bias, as evidenced by the following quote offered by one of the participants: "They [school counselors] worry about certain people for so much, but they don't worry about all of them" (Moore, Henfield, & Owens, 2008).

Marginalized Client Access to VR Services and Quality of Services

Wilkerson and Penn (1938) conducted a large-scale study reporting the disparities in the federally funded civilian vocational rehabilitation (VR) system. Similar results were found in studies on African Americans receiving vocational rehabilitation services (Atkins & Wright, 1980; Herbert & Cheatham, 1988; Wilson, Harley, & Alston, 2001; Wilson, Turner, & Jackson, 2002). Mwachofi (2008) examined African Americans' access to vocational rehabilitation services before the antidiscrimination legislation in 1937 and after the legislation in 2004 using RSA 911. The study found widening gaps between European American and African American consumers in education, employment, earnings, and per capita VR expenditures for services rendered.

Disparities in vocational rehabilitation services and outcomes for Hispanic clients revealed that European Americans were more likely to obtain employment than were Hispanics. In addition, Hispanics with work disincentives had lower odds of returning to work and had more unmet basic needs (e.g., food, shelter, transportation) that need to be addressed in the rehabilitation process. Although job placement and on-the-job support services were found to significantly improve employment outcomes, on-the-job support services were more likely to be provided to European Americans than to Hispanics (da Silva Cardoso et al., 2007).

American Indians have the highest rate of disability among marginalized groups and have the lowest opportunity for access to culturally sensitive programs and services of all races (NEA, 2003) (see Chap. 13 for discussion on American Indians). The US Census projects that Asians and Pacific Islanders will grow proportionately more than any other marginalized group in the country and estimates that 13% have some type of disability. Asian and Pacific Islanders have not been studied extensively, in part, because of the wide range of ethnicities that comprise the population and the differing economic and social histories of each (Probst et al., 2002). However, one study conducted by Park, Kim-Rupnow, Stodden, and Starbuck (2005) demonstrated that Asian Americans and Pacific Islanders (21%) were less likely to be accepted than European Americans (17%), and of those accepted, Asians and Pacific Islanders (35%) had less successful closures than European Americans (43%).

In contrast, research on consumers with sensory disabilities reported mixed or conflicting findings with regard to racial disparities. For example, Giesen, Cavenaugh, and Sansing (2004) reported that African Americans who were legally blind or had visual impairments accessed the state-federal VR system at a higher percentage rate than their percentage in the general population of those who were legally blind or had visual impairments, while those who were European Americans and legally blind or had visual impairments accessed VR at a lower rate than their percentage in the general population of persons who were legally blind or had visual impairments. They attributed these results, were in part, due to increased outreach to marginalized groups with visualized impairments. These researchers also suggested that the results might have been associated with preexisting socioeconomic disadvantages, higher unemployment, lack of health insurance, higher numbers of single-parent families, and greater receipt of public support. Another study examining the VR outcomes among European Americans and Latino consumers with hearing losses found that consumer ethnicity was not significantly associated with successful VR outcome (Bradley, Ebener & Geyer, 2013). These researchers suggested that one plausible reason for this insignificance of ethnicity among consumers in this study only involved Latinos who identified themselves as European American.

Rehabilitated closure is a strong indicator of successful VR service outcomes. Extant studies have found disparities in the employment outcomes among specific disability groups. For example, Catalano, Pereira, Wu, Ho, and Chan (2006) found that European Americans (53%) with traumatic brain injuries (TBI) had appreciably higher competitive employment rates than American Indians (50%), Asian Americans (44%), African Americans (42%), and Hispanic/Latino Americans (41%). However, Johnstone, Mount, Goldfader, Bound, and Pitts (2003) found no significant difference in the number of successfully employed African American rehabilitation clients with traumatic brain injury (23%) versus European Americans (18%) in a midwestern State Vocational Rehabilitation Agency. Interestingly in that study, African Americans (92%) were more likely than European Americans (58%) to live in urban areas. Among young adults with specific learning disabilities, transitioning from school to work, European Americans had higher competitive employment rates (64%) than African Americans (20%), Hispanic/Latino Americans (13%), Asian Americans (1.5%), and American Indians (1.2%) (Gonzalez, Rosenthal & Kim, 2011). In another study examining the employment outcomes of individuals with spinal cord injuries over a period of 3 years, the majority of the individuals whose cases were closed successfully employed were European Americans (82%), followed by African Americans (16%), Hispanic/Latino Americans (8%), American Indians, and Asian Americans (1%), respectively (Inge, Cimera, Revell, Wehman, & Seward, 2015). Cinnamond's recent dissertation study (2016) examining the rehabilitation and employment outcomes of Hispanic/Latino Americans over a 17-year period (i.e., 1997–2013) shows promise for increased employment outcomes in the new immigration destination (i.e., Southeast) versus the traditional settlement (i.e., Southwest) for Hispanic/Latino Americans; however, the employment rates in comparison to European Americans in both areas remain disparate. With few exceptions, research documents the fact that the employment outcomes for members of marginalized groups continue to lag behind those of European Americans in the State VR system.

Counselor-Client Working Alliance with Marginalized Clients

The working alliance (Bordin, 1979) is defined as a collaboration between the client and the counselor based on the development of a bond and shared commitment to the goals and tasks of counseling. The foundation for development of the working alliance is a counselor with a good attitude and a good rapport with the client. The ingredients of a working alliance are a collaborative effort, equal contributions from the client and counselor, and active participation between the counselor and client. These ingredients of care combine to meet the goals (agreed upon objectives), tasks (agreed upon behaviors), and bonds (level of empathy) (Lustig, Strauser, Rice, & Rucker, 2002). The working alliance consists of both the quality and strength of the reciprocal relationship (Bedi, Davis, & Arvay, 2005). Generally, the working alliance influences client outcomes and is a salient counseling component across cultures (Asnaani & Hofmann, 2012; Vasquez, 2007).

Building trust and collaboration with marginalized clients and their communities is paramount in achieving positive outcomes. The counselor or service provider must be cognizant of the historical-social-political context of marginalized groups in the United States. It is not uncommon for the counselor, especially one from outside of the client's membership status and especially European American counselors, initially to be met with suspicion, distrust, and, to a certain extent, historical hostility. Thus, the counselor needs to have a working knowledge of cultural attributes of marginalized clients in rural areas, as well as how these clients define themselves within the context of community. The fact that RFT residents generally interact and live in a geographically defined place, those interactions shape the structures and institutions of the locality, and those structures and institutions in turn shape the activities of the people with whom they interact (Beckley & Weathersby, 2005). For racial and ethnic marginalized groups in rural areas, the "density of acquaintanceship" is one of the bases by which the community builds a sense of solidarity and ultimately how they build a sense of solidarity through interactions with one another (Flora et al., 1992, p. 68). Expanding on Flora et al.'s assumption, counselors should consider that frequent interaction with marginalized clients might form the basis for acquaintanceship and potentially a better working alliance.

Chang and Yoon's study (2011) indicated that the majority of marginalized clients believed that European American therapists could not understand key aspects of their experiences and subsequently avoided broaching racial/cultural issues in therapy. However, many felt that racial differences were minimized if the therapist was compassionate, accepting, and comfortable discussing racial, ethnic, and/or cultural issues. These results support recommendations that therapists acquire and expand their expertise to deliver culturally appropriate services to address the needs of marginalized clients.

One key aspect of improving the working alliance between the counselor and a marginalized client is for the counselor to be aware of the influence of microaggressions in the counseling process. The term *racial microaggressions* was originally coined by Chester Pierce to describe the subtle and automatic put-downs that African Americans face (Pierce, Carew, Pierce-Gonzales, & Willis, 1978). Microaggressions are defined as brief, everyday exchanges that send denigrating messages to a target group, such as people of color, people with disabilities, LGBTQ individuals, and religious minorities (Sue et al., 2007). Expressions of racism and discrimination have evolved over time into more subtle and ambiguous forms and in some ways have become more disguised and covert (Sue & Sue, 2015). However, this is not to say that overt and blatant acts of racism and discrimination do not exist.

Sue and Sue (2015) indicate microaggressions can also be delivered environmentally through the physical surroundings of target groups. Although rural areas are becoming more racially diverse, they are predominately European. For racial and ethnic marginalized groups living in these rural areas, the display of historical artifacts (e.g., pictures) in prominent buildings (e.g., courthouse, post office, city hall) sends a message that "your kind does not belong here." A similar message is sent to persons with physical disabilities when there is limited or lack of access to buildings. The occurrence of such microaggressions can (a) be subtle, unintentional, and indirect, (b) occur in situations where there are alternative explanations, (c) represent unconscious and ingrained biased beliefs and attitudes, and (d) more likely occur when people pretend not to notice differences (Sue et al., 2007). The result of microaggressions is that ethnic and racial marginalized groups can often feel like aliens or second-class citizens in their own land. It is important to understand how marginalized groups understand their environment. In addition, the fact that counselors possess unconscious biases and prejudices is problematic, especially when they sincerely believe they are capable of preventing them from entering the working alliance (Sue & Sue, 2015). Unintentional stereotypes and biases can undermine service providers' efforts to deliver quality services. Denial of unconscious biases by counselors is only one part of the challenges of service delivery to ethnic and racial marginalized groups residing in rural areas; the other is counselors and other human service workers may be inadequately prepared to address the needs of these populations (Hancock, 2005) (see Research Box 9.1 for perspective of registered nurses' cultural competence in a rural state).

Research Box 9.1

See Seright (2007).

Objective: The article is the second in a two-article series. The first article provides the readers a conceptual definition of cultural competence, a review of literature, and a description of the relevance of culturally competent care in a rural state. The purpose of this article was to determine the relationship between cultural competence and educational preparation.

Method: A voluntary sample of registered nurses from urban and rural hospitals in the state of North Dakota were surveyed using the Inventory for Assessing the Process of Cultural Competence-Revised version (IAPCC-R) and a demographic survey tool. It was hypothesized that nurses who reported participation in cultural competency educational programs would rank themselves higher on the IAPCC-R than those who had not reported participation in such programs. The data was analyzed using correlational statistics.

Results: A majority (>80%) of the participants did not consider themselves culturally competent. While higher self-rating scores did correlate to participation in educational activities, the quality and frequency of those activities vary.

Conclusion: Ongoing education, or cultural diversity training, at the workplace, positively impacted IAPCC-R scores more than any other variable. Although there were no significant correlations made between higher IAPCC-R scores and participation in a cultural diversity course within the respondents' nursing program, the survey participants did express a need and desire to learn more about those from other cultures.

Questions:

1. How can replication of this study be conducted across other disciplines and employment settings?
2. How can this study be conducted in other ethnically homogenous states and comparisons run between states?
3. How can the IAPCC-R be used as a benchmark and evaluation tool within facilities and human service agencies when they are evaluating their cultural diversity training programs?

Counselor Cultural Competence

The increased demographic shifts described earlier compel rehabilitation counselors to incorporate cultural competence into their practice when working with individuals from traditionally underserved marginalized groups, particularly those residing in rural America. Approximately three decades ago, Sue et al. (1982) identified minimal competencies for counselors to skillfully and knowledgeably serve clients from culturally diverse backgrounds, based on three domains: *awareness*, which involves becoming aware of one's own values, biases, assumptions about human behavior, preconceived notions, personal limitations, as well as the sociopolitical relevance of cultural group membership; *knowledge*, namely, about the ways in which cultural processes affect different groups (e.g., the effects of social stratification, acculturation, immigration, historical factors, institutional structures, individual meaning making); and *skills*, which includes the ability to effectively integrate the impact of cultural factors when actively practicing appropriate, relevant, and sensitive intervention strategies and techniques.

The newly adopted multicultural and social justice competencies (MSJCCs) add an additional domain, *action*, emphasizing the need to create maximum influence of counseling interventions (Ratts, Singh, Nassar-McMillan, Butler, & McCullough, 2016). Thus, culturally competent counselors are defined as those who have internal awareness of values and biases, extend this awareness to understand clients' worldviews, and subsequently determine, in collaboration with clients, interventions and strategies that are culturally responsive and that promote social justice through advocacy (Ratts, Singh, Nassar-McMillan, Butler, & McCullough). The MSJCCs encourage understanding of the context relevant to the lives of marginalized group members. Therefore, recognition of the following important aspects of counseling practice for both marginalized counselors and clients is vital:

(a) Understanding the complexities of diversity and multiculturalism on the counseling relationship
(b) Recognizing the negative influence of oppression on mental health and well-being
(c) Understanding individuals in the context of their social environment
(d) Integrating social justice advocacy into the various modalities of counseling (e.g., individual, family, partners, group) (Ratts et al., 2016, pp. 30–31)

This inclusive and broad understanding of culture and diversity requires that counselors acknowledge the existence of multiple identities and intersecting privileged and marginalized statuses, recognize that the social construction of identities cannot be understood in isolation, and realize that a client's environment influences which aspect of his/her identity is significant at that moment in time. Therefore, an understanding of intersectionality and the influence of oppression and discrimination on mental health and well-being, particularly among clients of color residing in rural areas, are critical components of cultural competency.

The MSJCCs are the catalyst that rehabilitation counselors may use as leverage toward quality and equitable services for all clients. We recognize that cultural competence is an active, developmental, and ongoing process. Rehabilitation counselors are encouraged to expand their knowledge and expertise by understanding the impact that culture has on behavior, attitudes, and values, the help-seeking behaviors of clients who are members of marginalized groups, the specific cultural customs, the role of language, speech patterns, communication styles of the varied client groups in the communities served, and the informal helping networks that may be used. To that end, a case study follows demonstrating Shauna's interactions with a client to illustrate the value of cultural competency awareness in working with this client.

The Case of Mahealani

Mahealani is a 19-year-old young woman who was diagnosed with spina bifida, hydrocephalus, hypertension, and obesity. Mahealani uses a wheelchair and sometimes her crutches; she has no limitations with her upper body. While in high school as a transition student, she was referred to Shauna. Mahealani presented with a career decision-making dilemma and also shared that she was having difficulty adjusting to her move from Hawaii to the mainland in the rural south. In reference to her career issues, she realized that she now has to give up her childhood dream of becoming a massage therapist. The closest training program is located 6 h away, farther away from her family and social support system, with fewer housing accommodations, less transportation options, and less accessible healthcare resources. Mahealani then confided that prior to her move to the south, her identity as a Nativve Hawaiian was never questioned. Here, only her African American heritage was acknowledged, forcing her to always explain. To fit in with her friends who are also bisexual, she is considering multiple body tattoos. However, she wonders how this may affect her future career choices.

Shauna is a rehabilitation counselor who self-identifies as an American Indian/African American working in a rural Southern State VR agency. The following culturally sensitive practices are gleaned from Shauna's experience as a service provider. First, the key consideration was the counselor-client match; both were members of marginalized groups. Shauna was able to build trust with Mahealani by sharing obstacles she too faced as a biracial person. This supports the results from Bellini's (2003) study which demonstrated significant main effects as well as complex interaction effects among client race, counselor race, and counselor multicultural competency in relation to rehabilitation rate and vocational training rate. Thus, clients from different racial groups experience different outcomes in the VR process in this agency as a function of the counselors' race and cultural competency. Second, Shauna respected Mahealani's worldviews without imposing negative judgments or invalidating her feelings in regard to fitting in with her peers. And third, Shauna had no problem extending her role beyond the traditional office setting to collaborate with community allies to assist Mahealani to pursue her new goal as a medical coder at the local community college.

Implications and Recommendations for Rural Rehabilitation Service Delivery

The MSJCCs compel counselors to move beyond self-reflection and awareness by adopting a professional commitment to action and collaborating at social, community, and institutional levels to ensure social change. In a study to identify the best method of building trust and collaboration with rural marginalized farmer in the Mississippi Delta, Mwachofi (2012) found that trust and collaboration building took several steps: (a) communicating individually with key community members, (b) getting insider involvement in the project administration, (c) gathering more background information about the focus population, (d) meeting farmers on their turf and on their terms, (e) gaining acceptance by officers of farmers and organizations, (f) recruiting interviewers and focus group facilitators from among the farmers, and (g) convening follow-up meetings with farmer interviewers. Each of these steps emphasizes the importance of involving the target party and community in the process. Counselors and other human service providers can learn from Mwachofi's steps in the delivery of services. Often, human service providers have procedures and policies to follow in the delivery of services. It would be prudent for them to look for ways to modify the protocol and to seek input from their clients about effective approaches to use in rural areas. Doing so does not promote violations of agency policies and procedures; rather, it promotes elements and advantages of empowerment and community-based action.

Lee, Carlson, and Senften (2014) examined the relationships between families' perceptions of cultural competence, therapeutic alliance, and practice outcomes in rural practice settings of social workers and found provider competence in rural culture was positively associated with practice outcomes (i.e., consumer satisfaction and hopefulness). Lee et al. recommended:

1. To achieve cultural competence, service providers need to receive, understand, and interpret information from clients in a culturally competent and sensitive manner (e.g., "think, feel, and act in ways that acknowledge, respect, and build upon ethnic, sociocultural, and linguistic diversity") (Lynch & Hansen, 1993, as discussed in Cox, Sullivan, Reiman, & Vang, 2009).
2. Practitioners need to ensure that the presenting problems and issues are understood as the consumer understands them and process them in culturally appropriate and relevant ways.
3. Service plans must also be conceptualized and organized with identified cultural values (Simmons, Diaz, Jackson, & Takahashi, 2008).
4. Because consumers need services from other agencies, in rural communities there are fewer formal resources, and other agencies are likely to be informal and may not be listed in a directory of social services. For better practice outcomes, providers need to identify and use informal as well as formal resources in order to provide culturally competent services from community collaboration.

Culturally competent providers are able to match services that support clients' cultural values and then incorporate the appropriate interventions (Lum, 2011). For example, ethnic and racial marginalized populations may rely on their church for services beyond religious and spiritual support. Culturally competent providers should consider strategies to incorporate this important informal support into delivery of services to the client as a means of overcoming resource barriers.

Finally, addressing the service needs of ethnic and racial marginalized populations in rural areas, service providers will need to understand how disparities in the provision of services disproportionately affect outcomes. Thus, the one-size-fits-all approach to services is not necessarily an effective approach to working with these groups. Furthermore, the intersectionality of identities (e.g., gender age, race) should be weighed in understanding how ethnic and racial marginalized groups interact with their rural environment and its influence on their receptiveness to services (e.g., independence, mistrust of the system). This process of introspection is at the core of the helping professions.

Summary

Racial and ethnic marginalized groups living in RFT communities represent distinctive groups and present with unique concerns for service delivery. Culturally competent counselors must be knowledgeable about the remnants of discrimination and microaggressions that have resulted in disparities in access, eligibility, quality, and types of services provided, types of closures, and employment outcomes of members of marginalized groups living in rural areas who need VR services. They must also commit to delivering services that embrace beliefs, customs, traditions, and history of members of marginalized groups living in rural areas. Insensitivity to these areas will continue to result with underserved clients from these groups and others who terminate services prematurely or under use services.

Resources

National Black Disability Coalition: http://www.disability.gov/resource/national-black-disability-coalition

Disability Justice: http://www.disabilityresources.org/HISPANICS.html

Understanding Prejudice: http://www.understandingprejudice.org/demos/

Positive Propaganda Advocacy & Empowerment: http://www.positivepropaganda.com

Project RACE: Reclassifying All Children Equally: http://www.projectrace.com

National Congress of American Indians: http://www.ncai.org/

Consortia of Administrators for Native American Rehabilitation: http://www.canar.org/

Initiative on Asian Americans & Pacific Islanders: https://www.whitehouse.gov/aapi

Center for Multilingual Multicultural Research: Asian-Pacific Island Resources: http://www.bcf.usc.edu/%7Ecmmr/Asian.html

Alaska Native Heritage Center: http://www.alaskanative.net/

The African Americans: Many Rivers to Cross: http://www.pbslearningmedia.org/collection/the-african-americans-many-rivers-to-cross/

Alaska Native Communities on Harriman's Route: http://www.pbs.org/harriman/1899/native.html

PBS Learning Media: Latino Americans: http://www.pbslearningmedia.org/collection/latino-americans/

Asian Americans: A Model Minority: http://www.pbs.org/video/11512028463/

Pacific Heartbeat: A Place to Call Home: http://pbshawaii.org/tag/pacific-islanders/

Learning Exercises

Self-Check Questions

1. Explain what is meant by rural marginalized individuals with disabilities are considered to have a triple minority status.

2. What issues must be considered in determining how racial and ethnic marginalized groups define disability and chronic illness?
3. What are some things you can do to ensure that microaggressions do not occur in your counseling process with clients who are members of marginalized groups?

Experiential Activities

1. Interview an individual with a disability who is a member of a marginalized group residing in a rural area to (1) assess barriers in accessing healthcare and rehabilitation services, (2) identify their perceptions of the quality of services in the State VR agency, and (3) then compare and contrast your findings with those in the Eide et al. (2015) study found at DOI:10.1371/journal.pone.0125915.
2. Interview five individuals with disabilities who are members of marginalized group residing in a rural area to assess the barriers to voting in the general election.

Attend a church with a majority membership from a marginalized group. Interview a prominent member of that community (e.g., religious leader) to learn about the services provided to the congregation.

Multiple-Choice Questions

1. Microaggressions are defined as ____.
   (a) Positive statements about a targeted group
   (b) Denigrating messages to a targeted group
   (c) Historical messages about a targeted group
   (d) Culturally specific characteristics of a targeted group
2. Which of the following statements is generally true of racial and ethnic marginalized groups?
   (a) They seek mental health services at the same rates as European American populations.
   (b) They are very open about acknowledging psychological problems.
   (c) They are significantly less likely to seek mental health services.
   (d) They are less likely to have mental health in comparison to European Americans.
3. Which of the following explain some of the differences in help-seeking behaviors of racial and ethnic marginalized groups for depression?
   (a) The way symptoms are manifested
   (b) The way depression is defined
   (c) The way symptoms are interpreted and labeled
   (d) All of the above
   (e) None of the above
4. Which of the following has been added to multicultural competencies by the multicultural and social justice competencies?
   (a) Awareness
   (b) Knowledge
   (c) Skills
   (d) Action
5. Which of the following most influences how we view people with disabilities?
   (a) Age
   (b) Gender
   (c) Culture
   (d) Religion
6. What are typical complicating factors impacting the well-being of marginalized groups residing in rural areas?
   (a) Lowered unemployment rates
   (b) Increased on-the-job support
   (c) Greater disparities in access to healthcare resources and availability of quality healthcare
   (d) Increased VR outreach
7. Which marginalized group has research reported mixed or conflicting findings with regard to racial disparities in employment outcomes?
   (a) Hispanic/Latino Americans with hearing losses
   (b) American Indians with traumatic brain injuries
   (c) African Americans with spinal cord injuries

   (d) Asian American/Pacific Islander young adults with specific learning disabilities
8. Which of the following is a key component in a counselor's understanding of the existence of the intersectionality of multiple statuses impacting the well-being of an African American gay male?
   (a) Client worldview
   (b) Cultural competency
   (c) Counselor self-awareness
   (d) Advocacy intervention
9. What components are paramount in achieving positive outcomes in a working alliance?
   (a) Building trust and collaboration with marginalized clients and their communities
   (b) Developing a thorough knowledge of cultural characteristics of marginalized clients
   (c) Reducing early termination
   (d) Avoiding racial/cultural issues
10. Which of the following areas does research not demonstrate that disparities exist in VR service provision to marginalized group members?
   (a) Closure types
   (b) Employment outcomes
   (c) Eligibility
   (d) Work disincentives

Key

1 – B
2 – C
3 – D
4 – D
5 – C
6 – C
7 – A
8 – B
9 – A
10 – D

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Adolescents and Transition Students with Disabilities in Rural Areas

10

Lisa Dunkley, Maram Alfulayyih, Lebogang Tiro,
Byung Jin Kim, and Debra A. Harley

Overview
Transition services are activities and experiences that prepare students with disabilities to move from school to postsecondary environments and events. Transition services are individualized and based on the student's needs, interests, and preferences and are person-centered, planned with interagency collaboration, and inclusive of activities promoting movement from school to post-school (Flexer, Simmons, Luft, & Baer, 2008), and shall include activities in instruction, related services, community experiences, development of employment, and other postsecondary adult living objectives, acquisition of daily living skills (when appropriate), and functional vocational evaluation (Individuals with Disabilities Education Act [IDEA], 1990; Wright & Wright, 2007). Proportionately, a greater number of vocational rehabilitation transition-age clients reside in rural communities than urban areas (Rehabilitation Services Administration [RSA 911], 2009). In comparison to urban transition students, rural students have lower rates of employment and enrollment in postsecondary education after graduation (Cobb et al., 2013; Harvey, 2002). In addition, rural transition students have limited job opportunities, limited access to counselors (Goe & Ipsen, 2013), and lower levels of social visibility and social connections (Farmer et al., 2011).

In a study to explore rural service delivery strategies, Goe and Ipsen (2013) found VR personnel considered transition services as important in rural VR service delivery. Several key findings resulted from this study. First, VR personnel identified outreach as a necessary first step for effectively serving rural transition students, with local connections with school officials and transitions teams as imperative to making service work and maintaining connections in rural area. Second, regardless of the structure of service delivery (i.e., assignment of a VR counselor to individual schools, a counselor to a special territory serving multiple schools, or a dedicated transition counselor serving multiple schools across a region), VR's involvement with transition students generally began in the student's junior year or earlier. Involvement in the individualized education plan (IEP) meeting was the primary form of contact with transition students. However, counselors were unable to provide services to students with less severe disabilities because of order of selection (OOS). Order of selection is a system organized by

L. Dunkley (✉)
University of Kentucky, Lexington, KY, USA
e-mail: lisa.dunkley@uky.edu

M. Alfulayyih • L. Tiro • B.J. Kim
EDSRC Department, University of Kentucky,
Lexington, KY, USA

D.A. Harley
Department of Early Childhood, Special Education,
and Rehabilitation Counseling, University of
Kentucky, Lexington, KY, USA

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priority categories of disabilities based on how significantly disability impacts opportunity to work. Those with the most significant disability are given priority category one, then a person with a significant disability (priority category two), and all other eligible persons in priority category three (Arizona Department of Economic Security, n.d.). The result was longer wait time until well after graduation and a significant gap in services. Finally, clients received either career counseling or college counseling, which included job experiences and job exploration (interest testing and reviewing the labor market and related salaries) (Goe & Ipsen, 2013). Although these services provided rural students the opportunity to become familiar with assistive technology and gain job experiences, limited counselor resources and lack of transportation were difficulties to setting up job experiences in rural areas. In addition, because of the "No Child Left Behind" policy, schools were less willing to provide vocational programs so that students could attend classes in preparation for standardized tests (Goe & Ipsen, 2013).

Rural students with disabilities and rural schools face numerous barriers to programming and service delivery including limited funding and resources, geographic and social isolation, small size, transportation, and limited access to trained and qualified personnel (Dempsey & Stephens, 2011; Richards, 2004), and students with disabilities are more likely to have negative perceptions of school and lower postsecondary aspirations (Irvin et al., 2011). In addition, the type of school setting may be another barrier for students with disabilities in rural settings. For example, Eigenbrood (2005) found services for students with disabilities in rural faith-based schools were more limited than public school settings. Faith-based rural schools had (a) fewer students identified with disabilities, (b) less special education training for their special education teachers, and (c) less use of certain related services. Yet, another aspect that can influence the encounter of students with disabilities in rural areas is cultural factors. For example, rural American Indian children and families must contend with a myriad of special education agencies and subsequent policies (e.g., laws represented by the USA, the state, the Indian Nation, and the local school district from the child's birth to adulthood) (Collette, 2013; see Chap. 13 for more information on American Indians). Finally, school administrators and service providers who are linked to the provision of special education and related services perceive the greatest areas of need were for highly qualified personnel with the necessary skills and knowledge to meet the needs of students with low-incidence disabilities (e.g., head/hard of hearing, blind) in rural areas and for timely information that would support the education of these learners (Harvey et al., 2005).

Learning Objectives
Upon completion of this chapter, the reader should be able to:

1. Identify the components of transition planning.
2. Identify barriers to transition services in rural communities.
3. Understand characteristics of transition populations in rural areas.
4. Identify key participants in transition planning.
5. Understand the role of family participation in transition services.

Introduction

The purpose of transition services is to prepare students with disabilities for life after high school. Transition services are to be coordinated activities (e.g., vocational training, employment, adult services, living arrangements; see Table 10.1 for major categories of transition services). The federal law, *Individuals with Disabilities Education Act* (IDEA), requires that an Individual Transition Plan (ITP) be written by the time a student is 16 years of age, and some states may require the ITP by age 14. The ITP is written by a team of professionals, the student, and parents that outline the training and support that will be necessary for the student to live, work, and participate in the community as an adult. In 2004, IDEA revised transition planning to (a) "be focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from

Table 10.1 Categories of transition services

Instruction – academic requirements for the student's chosen course of study, employment skills training, career technical education, social skills, self-determination, driver's education, and college entrance preparation
Related services – occupational/physical/speech therapy, counseling, special transportation, travel training, exploring disability
Support services – college or other professional supports may help to move the student toward post-school outcomes
Community experiences – community work experiences, recreation/leisure activities, tours of postsecondary education settings, residential and community tours, volunteering and training in accessing community settings, joining a team/club/organization
Employment – career planning, job shadowing, guidance counseling, interest inventories, job placement, internship options, on-the-job training, on-campus jobs, or supported employment
Adult living skills – referral to vocational rehabilitation services, researching social security benefits/work incentives, registering to vote, exploring residential options, and using navigation systems of the community
Daily living skills – self-care training, health and wellness training, independent living training, and money management
Functional vocational evaluation – situational work assessments, work samples, work adjustment programs, aptitude test, and job tryouts

Adapted from Autism Society of North Carolina (2016).

school to post-school activities" [Section 602 (34)], (b) appropriate measurable postsecondary goals be based upon age-appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills, and (c) transition services (including courses of study) needed to assist the child in reaching those goals ([34 CFR 300.320(b)]; Authority 20 U.S.C. 1414(d)(1)(A) and (D)(6)]). The most recent reauthorization of IDEA introduced the concept of "response to intervention" (RTI) which is a tiered process ranging from least to most restrictive learning environment (tier 1 to tier 3). Part B of the IDEA was published in August of 2006, which deals with school-aged children, and part C was published in September of 2011 which deals with babies and toddlers (Graves, 2012).

The concept of transition includes various aspects of adult adjustment and participation in community life (Gargiulo, 2009). However, the availability of resources to support transition services often varies between rural and urban schools. Rural schools and communities are distinct from suburban and urban schools, as well as from one another in population composition, level of income, and level of poverty, and more students are eligible for free or reduced lunch (Hull, 2003). According to the Institute of Educational Sciences (IES, 2013), in 2010–2011 about one-quarter of all public school students were enrolled in rural schools. In 2013–2014, approximately 6.5 million (13%) children and youth (ages 3–21) were receiving special education services in public schools, and 35% of students receiving special education services had specific learning disabilities (IES, 2016). The Alliance for Excellent Education (2010) emphasized the need for federal solutions that effectively address the following issues in order to ensure that rural high school students are prepared for postsecondary education and employment (a) ensuring fair and adequate federal investment, (b) providing high standards and demanding courses, (c) improving rural high school accountability, (d) expanding student supports and options, (e) recruiting and retaining highly effective teachers, (f) building strong models of community support, and (g) setting high expectations for college and career success (pp. 4–5).

In a study of the quality of postsecondary transition plans against research-based criteria in preparing rural students with disabilities for postsecondary success, Miller-Warren (2015) found the majority of ITPs were inadequate in quality. That is, the plans were not well written and were "not sound" plans based on the literary criteria, and systematic assessment of the quality of the plans did not occur at the secondary level (p. 11). Overall, the ITPs failed to meet both federal and state mandates that students with disabilities engage in secondary transition planning activities that facilitate their movement into postsecondary success and all students are entitled to sufficient skills to successfully engage in postsecondary education and employment.

Miller-Warren concluded despite such laws as IDEA, the Rehabilitation Act, and the Americans with Disabilities Act, students with disabilities graduating high school continue to face significant challenges when it comes to postsecondary success in the areas of employment, education, and independent living. Finally, the majority of the secondary ITPs were written as pro forma (required but with little importance) and were not properly designed to meet the needs of the students in preparing them for postsecondary success (Miller-Warren, 2015).

The remainder of this chapter will explore challenges to characteristics of transition in rural areas and discuss family involvement in the transition process. Rural communities are really diverse, and some situations explained in the rest of the chapter may be representative of some rural communities but not all. Recommendations for transition service improvement will be provided as well as recruitment improvement techniques used in some rural communities for special education teachers. The multidisciplinary approach often utilized in the transition process will be explored, and the role of parents/family will be examined.

Characteristics of Rural Students with Disabilities

Rural school districts comprise between 10% and 25% of school districts in the USA (Purcell, East, & Rude, 2005). When discussing rural school districts, it is important to understand that population scarcity and remoteness are the key characteristics of rural communities. The US 2010 Census Bureau defines a rural area as an area that is not urban. "Urban" is defined as either an urbanized area or places with populations of 2500 or more outside urbanized areas. An urbanized area includes places and their adjacent densely settled surrounding territory that together have a minimum population of 50,000 (Bureau of the Census, 2010). Rural school districts are responsible for the proper education and employment of their students and teachers. Overall, all school districts, rural or urban, strive to provide high-quality education with their means and resources. However, rural school districts have some unique challenges in meeting the needs of their students. These challenges are more so when meeting the needs of their students with disabilities in rural school districts.

Students with disabilities in rural communities share many characteristics with students in urban and more populated communities. However, there are some characteristics that are more prevalent in students with disabilities in rural areas in comparison to those in urban communities. Specifically, rural students show significant difference in socioeconomic status, access to English as a second language and English proficiency teachers, and low expectation of education (National Center of Educational Statistics, 2016; Pennington, Horn, & Berrong, 2009; Smink & Reimer, 2005). With mass immigration and globalization, English language learning (ELL) programs are now greater in urbanized school districts (National Center of Educational Statistics, 2016). Overall, students in rural communities have limited English proficiency in comparison to their urban counterparts. However, providing services, programs, or classes to increase English proficiency remains a challenge in rural areas because of limited access to specially trained staff. The challenge is more compounded when considering that rural school districts fail to attract special education teachers due to low pay rates and lack of teaching resources (Pennington, Horn, & Berrong, 2009).

The 2010 US Census Bureau reports 2.8 million (5.2%) of school-aged children are reported to have a disability (Brault, 2011). Children in metro areas were provided with more education options than those living outside of metro areas. In addition, children living outside metro areas had a higher level of disability (6.3%) than those in metro areas at 5%. Of the states sampled in the census, children living outside metro areas had higher disability rates across disability types except for a few states (Brault, 2011). The United Nations International Children's Emergency Fund (UNICEF) indicated that children with a lack of access to resources and healthcare and exposed to poor working and living conditions are more likely to become disabled. Moreover, poverty and disability reinforce each other and add to vulnerability and exclusion in the community (UNICEF, 2013). Furthermore, the US Census Bureau reports about 13.3% of people living in rural areas live in families with income below the official poverty threshold.

Another area of difference between rural and urban community districts is academic expectations of achievements. The lower the income level and the more rural a community, the lower the academic achievement expectations were for their students, especially, those students with disabilities (Smink & Reimer, 2005). Many families do not see education as a means to a better future for their children. The communities' culture, political orientation, and local job market affect the way families view the importance and role of education for the students in their communities (Roscigno & Crowley, 2001; Roscigno, Tomaskovic-Devey, Crowley, 2006).

Though students with disabilities throughout the nation face similar challenges, students in rural communities have different challenges posed by their unique characteristics. As discussed earlier, the three major characteristics of students in rural communities are their low-income or socioeconomic status, lower rates of English proficiency, and low expectations of academic achievement by their educators. Though these challenges are systematically rooted in the culture for educating students in rural communities, they can be challenged. One way to challenge these characteristics is to attract high-quality educators to rural areas by increasing pay, offering incentives, and providing resources such as distance education learning programs. Also, rural communities can work with their school district in designing after graduation transition programs for their adult students with disabilities. Though these alternatives will require funds and time, they are steps that will improve the quality of education and opportunities for students with disabilities in rural communities.

Challenges in Special Education Programs

In rural communities, postsecondary educational aspirations of students are often impacted by geographical and economic boundaries (Richards, 2004). Many adolescents with disabilities such as learning disabilities and emotional disorders experience poor transitioning outcome (Trainor, Morningstar, & Murray, 2016). Furthermore, these individuals are more likely to drop out of school than their urban counterparts. Richards goes on to state rural students with learning disabilities encounter limited local occupational opportunities. Thus, they must contend with whether to leave their rural communities to expand career opportunities and to advance their education. Limited school curricula and difficulties with poverty significantly impact access to resources and information needed to succeed in postsecondary settings. In addition, service providers in rural communities with an understanding of the federal, state, and local transition policies and mandates who assist individuals with disabilities are limited. Moreover, professionals working with students with disabilities with the transition process may be limited in their abilities and experiences working in a rural setting (Richards, 2004). Professionals may not be familiar with the transition process, may have credentials in other areas of teaching different from special education, and may have limited knowledge about the characteristics of rural communities.

Recruitment of Qualified Teachers

Special education teachers serve a vital role in the transition process for individuals with disabilities. In rural areas, critical shortages and difficulties with recruitment, retention, and supply of special education teachers and administrators has been ongoing and is difficult to address (Dempsey & Stephens, 2011). Another compounding issue to the challenge of recruitment and retention is that smaller schools in rural areas are perceived as stepping-stones for teachers and administrator to move on to suburban schools. Teachers move to these areas in the hopes of getting better pay, increased access to resources, and possibly fewer classes for which to prepare. Limited financial support adds to the strain of staffing problems in rural areas. Schools with limited funding may limit the range of curricular options and course placement options (Dempsey & Stephens, 2011) which may significantly impact the transition planning process for students with and without disabilities. As previously mentioned, high turnover rates and difficulty attracting new teachers may be because of salary limitations. With few teachers and administrators to carry out duties, many must perform multiple roles, which may include roles beyond their expertise (Dempsey & Stephens, 2011).

An increase in the need for special educators is exemplified by the increase in students in special education programs. The shortages of qualified educators have produced an influx of individuals filling special education positions for which they are not certified. This is an important factor as researchers have shown there is a correlation between teacher's qualifications and student achievement (Canter, Voytecki, & Rodriguez, 2007). Canter et al. (2007) state one recruitment effort to meet the needs of students living in rural areas is to recruit preservice teachers and the use of distance education to allow access to higher education and special education instruction. Sutton et al. (2014) highlighted the use of "grow your own" programs to combat the shortage of special education teachers in rural areas. They describe these programs to include alternative routes to certification for teachers, tuition and textbook assistance programs, and reeducation centers for teachers. However, questions remain about the distribution of qualified teachers from capacity-building efforts to hard to staff, low performing, and high poverty schools found in rural areas (Sutton et al., 2014). Despite efforts to improve staffing issues and access to education, teacher preparation programs struggle to effectively track, assess, and provide timely feedback for teachers to make necessary adjustment in the implementation of evidence-based practice (Bondie, 2015). In addition, lack of access to assistive technologies and instructional resources may have special educators assisting family members beyond their expertise with finding and or providing support services difficult to source in rural areas (Sutton et al., 2014). Furthermore, most rural school districts offer very little to no professional development programs resulting in special education teachers feeling professionally isolated with no means or opportunity to grow professionally as an educator (Pennington, Horn, & Berrong, 2009).

Low Expectations

There are a few assumptions to explain this lack of high expectations by families and educators of students with disabilities. One assumption is special education teachers in rural areas are often isolated and do not have access to funds, technology, support, and knowledge to provide high-quality education to a student with disabilities (Collins, 2007). An additional assumption is that teachers may feel there is no real need for students with disabilities to achieve high because they may not have many opportunities to live and earn independently after graduation because there is often a lack of transition options for students with disabilities in rural communities. Collins (2007) explains that even when students with disabilities acquire functional skills to be independent and self-sufficient, many rural communities have very little or no options for people with disabilities to work or live independently. Many rural communities do not offer apartments for supported living, public affordable transportation, or proper accommodations for people with disabilities. Therefore, many students with disabilities find themselves living at home with no opportunity for independence after graduation. According to Morris (2005), low expectations that create enormous barriers for people with disabilities are attributed to (a) attitudes that people with disabilities are commonly considered to be in need of care, and this undermines people's ability to see people with disabilities as autonomous people, and (b) people with disabilities are often treated as not belonging to communities in which they live. Furthermore, expectations may be influenced further based on type and severity of disability, the more severe the disability, the lower are expectations.

Another consideration is the unintentional outcome of offering multiple paths in high school graduation requirements to students with disabilities. That is, many states currently offer alternative types of diplomas, skills certificates, or modified diplomas for students with disabilities that were intended to "provide students with access to future educational and work opportunities instead actually limit students in achieving these goals due to a lack of understanding and acceptance of alternative diplomas by postsecondary programs and employers" (Stansbury, 2013, p. 1). In the report on *Diplomas at Risk* by the National Center for Learning Disabilities (Coulter et al., 2013), the more diploma options offered to students, in fact, result in fewer high school graduates. According to McGrew and Evans (2004), expectancy effects for students with disabilities in the context of both IDEA and No Child Left Behind (NCLB) may lead to inappropriate and unrealistic academic expectations for these students, especially those with cognitive disabilities. Finally, attribution theory (Bandura, 1977) is considered an important theory with regard to teachers' expectations of students and their performance. In a study of preservice teachers' attributions of educational outcomes of students with learning disabilities, Vialle and Woodcock (2011) found general education teachers perceived students with learning disabilities as lacking ability in comparison to others in the class.

Job Placement and Employment

In rural areas, Kinnison, Fuson, and Cates (2005) reported parents of children with disabilities feared inadequate treatment of their children during the job training process. These parents did not have expectations of their children working in an inclusive setting but expected their children to be placed in sheltered workshops. A general economic decline in rural areas has negatively impacted the school to work transition programs, and parents are faced with the possibility of their children leaving for larger communities in search of opportunities. Factors associated with low employment in rural areas can be associated with several issues and vary across locations. Chronic poverty, intense competition for limited jobs, high school dropout rate, and low priority on job placement in IEPs are major contributors of rural challenges (Morgan & Openshaw, 2011). Also, access to transportation, isolation, and service availability may pose formidable barriers to employment for individuals in rural areas (Pullmann, VanHooser, Hoffman, & Heflinger, 2010).

Morgan and Openshaw (2011) summarize that young adults with disabilities who are employed post high school are likely to remain employed. However, individuals with disabilities in rural areas are less likely to be employed than those in urban areas. Sharac, Mccrone, Clement, and Thornicroft (2010) posit stigma exist in a myriad of settings including employment and can negatively affect access to services, vocational, and leisure activities. Access to employment is fundamental to post-school outcomes for young adults' economic well-being. When individuals with disabilities are stigmatized, employers may be reluctant to hire them, and this may affect the person on an individual and economic level.

Parents' Involvement

Parents play an important role in the transition process to help students with disabilities explore postsecondary opportunities (Miller-Warren, 2016). However, parent involvement in the postsecondary transition process may pose a challenge in rural areas owing to geographical distance and isolation. Difficulty collaborating with parents is exacerbated by the shortage of special education teachers, sometimes with only one at some school sites (Evans, Williams, King, & Metcalf, 2010). Parents express the need for continued and consistent communication from teachers throughout the transition process as they have their own goals for their children's future. Miller-Warren (2016) posits parents may not be very knowledgeable of the transition process and may have unrealistic goals for their children. Often, parents may feel confused during the individualized education plan (IEP) meeting and the planning process. Parents, teachers, and children may not always share the same vision as it relates to the transition planning process. It is the duty of the special educators to help parents to shape realistic views and enlighten them about the transition process as their input is very valuable. Culturally diverse and non-English-speaking families may face additional barriers in IPE meetings, as they may need the assistance of a translator due to meetings being predominantly in English. Translators may not effectively translate or communicate everything discussed at the meeting, and thus, parents are often left listening rather than actively participating in the IPE meeting.

Parents have played an instrumental role in the disability movement for the Individuals with Disabilities Education Act (IDEA), which contains the rights and protection for parents of students with disabilities and views them as an equal contributor to the special education process (Burke & Sandman, 2015). Parents may feel disempowered and unable to express their feelings and concerns in IEP meetings instead of being viewed as experts about their children. Parents may experience this disconnect to rural educators as Ludlow, Conner, and Schechter (2005) state rural educators have a greater sense of isolation and lack support in the school system. In very rural areas, some special educators may be the only one in the rural school or system. With this in mind, rural special education teachers may be overwhelmed and unable to create meaningful relationships with parents of children involved in transition planning. Parents want additional services covered by the IDEA and thus more supports for their children including a lower starting age for transition services from 14 to 12 years (Burke & Sandman, 2015). The more recent reauthorization of the IDEA has raised the age of transition planning from 14 to 16 years and requires appropriate measurable postsecondary goals in training, employment, and independent living skills (Hethering et al., 2010). Parents express deficiency in funding is stated to be an influential factor in their children receiving appropriate services required (Burke & Sandman, 2015) which is important in transitional goal attainment (Bridges & Maxwell, 2015).

Transitional planning, implantation, and success have been deemed difficult in rural areas and will need steps to create opportunities of interdisciplinary, student-focused, and family involvement to be successful. Some parents may not be fully aware of their rights and the laws relating to transition planning, and efforts need to be made to share information with parents in a manner they can understand (Matuszny, Banda, & Coleman, 2007). Parents are motivated to be a part of the transition process; however, they would like more knowledge and resources about the various components of the transition plan and services available post high school (Hawranick, 2013).

Student Diversity

The student population in rural schools is growing faster than in any other geographic area, and its student composition is becoming poorer and more racially diverse (Johnson, Showalter, Klein, & Lester, 2014; Strange, Johnson, Showalter, & Klein, 2012). Nationally, 26.7% of rural students are children of color, 75% of rural students of color attend school in the 17 states with rural minority student rates above the national average, and nearly 69% of all rural minority students in the USA are concentrated in the 13 states where they make up one-third or more of the state's rural student population. Across the USA, the Hispanic/Latino student enrollment is growing three times as fast in rural areas as in nonrural areas (Johnson et al., 2014). Developing positive classroom environments and access to general curriculum to foster success has become increasingly difficult as classroom environments become more diverse (e.g. race, disability, ethnicity, and socioeconomic status) and have seen a growing non-English language learner population (ELL, Evans et al., 2010). Evans et al. explain that many students struggle to learn and experience language and cultural barriers that put them at risk for school dropout. Native Americans Indians are more likely to be identified as having a learning disability (Blanchett, 2010). The increase in cultural diversity in public schools in special education classrooms reveals a lack of teacher competencies to assess, teach, and evaluate culturally and linguistically (CLD) diverse students with and without disabilities. Moreover, the acute shortage in special education teachers has seen little variation in a diverse background of special educators as majority are white and very few are males (Utley, 2011).

In a study of a cohort of preservice teachers' perceptions of their preparedness to teach diverse students in rural areas, Wenger and Dinsmore (2005) found teachers from these cohorts confront the challenges of meeting diverse learners' needs in rural school by frequently calling on their teacher friend networks for more materials, suggestions, and support. These teachers believed it is exhausting for new rural teachers to design curriculum with students whose lives are different from their own, Also, as novice teachers, they are surprised that schools consider them resources for dealing with diversity.

As mentioned previously and further discussed below, parent involvement with their children's educational process is important to student achievement and self-perception. Parents of English language learners in rural areas face additional challenges. Shim (n.d.) identifies three broad themes as obstacles that inhibit productive ELL parent-teacher interactions: (a) teachers' judgments toward ELL students and their parents, (b) ELL parents' frustration about their inability to influence a teacher's decision making, and (c) ELL parents' fear of repercussions for speaking up. Consider the below case study and how culturally competent special education teachers and services are needed in rural schools.

Case Study

Trinity County, California, has a small population of 13,786, according to the 2010 census report. The population is about 87% (12,033) white, 4.8% (655) Native American, 0.4% (59) African American, and 0.7% (16) Asians. There are approximately 500 students between the third and fourth grade in the county. Ms. Sharon is a 35-year-old American Indian first grade teacher in the rural Trinity County. She has been familiar with all her students and their families as a result of being born and raised in the community. She predominantly taught local white and American Indian students. She is very comfortable with teaching her students according to the state requirements and the culture of her community.

Recently, Jacob, a child of a refugee family from Kashmiri, has joined the class. Jacob's family is well educated, and he previously studied in a British medium school. There is no language barrier. He exhibits behaviors that Ms. Sharon is concerned about. Jacob is easily startled. He does not like to be held, rocked, or cuddled. Jacob avoids small play areas like the playhouse. Jacob does not fall asleep easily during naptime; if he does he wakes up startled and lost. Abrupt, and especially loud, sounds make him cry and try to flee the area. He constantly runs toward the door and cries to go out. Jacob does not like to engage in the classroom activities. Instead, he keeps to himself and repeats the same routine and steps that he learned the first day of class. Ms. Sharon is concerned about

Jacob. She wants to help Jacob. Jacob is exhibiting concerning behaviors to Ms. Sharon.

1. How do you address his behavior in his transition plan meeting?

2. Ms. Sharon is concerned about Jacob's career goals. Where would you recommend for her to go to seek knowledge, advice, support, and recourses to guide her?
3. Ms. Sharon is part of the minority group in her community. What challenges and strengths do these bring her when teaching Jacob?

Rural Families' Participation in Transition Planning

Transition to adulthood is an important stage in life for students with disabilities but also for their parents. Planning for transition provides parents with links to teachers, counselors, related service personnel, and postsecondary adult agency services (Rowe & Test, 2010). Transition planning in rural areas can be challenging. The transition process is important for the whole family, and its level of success affects the well-being of everyone involved. Rowe and Test (2010) stated that very few parents are highly involved in transition planning training. This suggests that parents are not taking part in the transition planning trainings being offered, so it seems important to explore alternatives to providing information to families. Another observation was that some studies found that families felt they did not play a role in transition planning because they were unsure of how they fit into the transition planning puzzle.

In their discussion, Rowe and Test (2010) stated that literature focusing on increasing parent and family involvement in the transition process consists primarily of conceptual discussions and recommendations from experts in the field about how to encourage parent participation and improve communication among all stakeholders involved with assisting students in transitioning from school to adulthood (e.g., providing ongoing communication and collaboration with families, including family resources and community members in planning). The discussion also indicated that family members were unfamiliar with the various adult agencies and their services, and in most cases, during transition team meetings, school professionals shared information and made decisions about transition programming without input from parents. Furthermore, parents felt they lacked understanding of the transition planning process and did not realize what transition planning entailed. In addition, Rowe and Test indicated that there was some evidence that parents lacked sufficient knowledge because parents assumed their children would automatically qualify for a sheltered workshop or some other day program due to the severity of their child's disability. Moreover, they believed these were the only postsecondary options available for their children. Beliefs such as these would eventually lead to parents having limited participation in the transition planning process.

In Australia, one study explained that few studies have focused on the issues faced by young adults with disability and their families in the transition-from-school period. In comparison to the USA, studies have noted negative findings related to both the transition process and post-school life for young adults with disabilities and their families. It was reported that the parents consistently reported low levels of family participation in the transition process and they also coordinated transition planning poorly. For the parents with young adults with more severe disability, the concerns that were identified were related to high levels of unemployment, restricted levels of participation in community activities, and a prevalence of continued living with and dependence upon families (Davies & Beamish, 2009). Though this study was carried out in Australia, it reveals challenges experienced in rural areas similar to that in the USA.

It is postulated by Magnuson (2013) that families of young adults with intellectual disabilities find high school transition more stressful than families of their peers without disabilities. Since some parents are hardly ever adequately prepared for transition of their loved ones with or without disabilities, the complications families face as a result of supporting members with disabilities are not new at the point of transition. A contributing factor might be because parents of children with disabilities also face transitions of their own.

The implications of the study noted that families receive little input from school and adult-based transition professionals, experience disruption and instability as their children exit secondary school settings, and struggle with a mix of positive expectations and anxieties about postsecondary planning outcomes.

The transition process is a time of significant change where teenagers and families must navigate developmental changes, increasing self-direction and independence of the adolescent from family, develop social and romantic relationships, and explore vocational opportunities. This change is experienced in adolescents with disabilities and may pose challenges from the possibility of additional complications due to disability or health-related issues (Timmons, Whitney-Thomas, McIntyre, Butterworth, & Allen, 2004). Timmons et al., through their review of the literature on transition, found that families adopt roles throughout the transition process as service developer, teacher and learner, advocate, decision maker, and primary supporter. Parents have to manage supports, services, and service systems from school and community agencies including those that provide adult supports. Parents report learning about services from their children's school and may include a network of opportunities ranging from education and vocational rehabilitation services to health-related services (Ankeny, Wilkins, & Spain, 2009).

Parents describe several challenges to negotiating complex relationships involved in the transition process or what Timmons et al. refer to as the "bureaucratic transition." They posit that parents perceive this system as being complex in its service delivery owing to the lack of coordination between all parties involved (agencies and schools). Parents describe the system as being unresponsive owing to the inability to respond to the need of their child. This may be due to lack of resources, staffing issues and difficulties related to inaccessibility. Furthermore, in dealing with the above issues, parents explain the continued task of advocating for their child as potentially exhausting, and they must ensure their own wellness to avoid burnout (Timmons et al., 2004). This is necessary as families are the providers of "backup services" where services otherwise fall short and may continue indefinitely into the child's life (Ankeny et al., 2009).

Families and parents of children with disabilities describe playing a continued role in their lives by promoting good work ethics, being supportive of vocational and independent goals. Ankeny et al. (2009) report high levels of parental involvement are correlated with more family resources and higher parental education, having two parent households, obtaining external funding, and belonging to family and children support groups. Parents want to ensure safety and stability with the increased social life that comes with independence. As it relates to independence, mothers do not see their role as supporter diminishing over time, as is sometimes the case of mothers of children without disabilities.

Transition to Adulthood and Postsecondary Life for Rural Students

Postsecondary life, which includes employment, poses a lot of challenges. Transition to post-school activities can be a daunting process for any individual as young adults try to establish independence and their own identity. For individuals with disabilities additional barriers to services, complicated policies and services requirements may be even more challenging (Foley et al., 2013) compared to their nondisabled counterpart. Key factors in successful transition from high school are having accurate knowledge about civil rights of individuals with disabilities and attitude and self-advocacy (Office of Civil Rights [OCR], 2011). In addition, OCR proposes high school educators encourage students to know the functional limitations that result from their disability and have the ability to explain their disability to disability coordinators if accommodations are needed (understand their disability). Young adults who are capable must take primary responsibility for their postsecondary outcomes and be able to advocate for themselves as parents may be less involved. Also, engaging in high school programs that will help with them to meet standards at whichever higher education institution they chose to attend. Learning time management skills is essential as young adults will be expected to manage their own time with little supervision connecting with vocational rehabilitation counselors, and other counselors can assist young adults with disabilities to identify resources to help with this (OCR, 2011). Counselors and high school educators can help students with disabilities and parents to research postsecondary school pathways and provide resources to assist with community involvement.

Parents

Transition to adulthood for young adults with disabilities shows parental support as a strong asset for this population. Parental roles may include providing material, emotional support, and continued advocates for services. Rossetti et al. (2016) postulate parents of young adults with intellectual and developmental disabilities (IDD) and pervasive support needs were actively involved as fierce advocates and creative problem solvers. The active involvement of parents included (a) attitudinal facilitators, (b) advocacy efforts and perceptions, and (c) strategic actions. The complexity of post-school avenues for students with disabilities deems family involvement an essential part of the post-school process (Davies & Beamish, 2009).

According to Ankeny et al. (2009), families may be seen as the only consistent source of support for individuals with disabilities post high school. By being an active supporter for their children, parents are in an informed position to evaluate the quality of services and program outcomes for their child (Davies & Beamish, 2009). On the other hand, Davies and Beamish highlight that there are positive and negative experiences documented in the literature of parents with children with disabilities. Parents of young adults with more severe disabilities have stated concerns related to high levels of unemployment and restricted community participation resulting in continued dependence on family members for support. Moreover, Davies and Beamish put forward that there are some studies that reveal some parents may play a minimal role in the transition process or postsecondary life for young adults with disabilities.

Based on the above discussion about transition, professionals implementing transition plans in rural areas experience additional resistance. Difficulties include too few resources like transportation, remoteness, financial and economic factors, and low population density. Collet-Klingenberg and Kolb (2011) studied secondary and transition programming for 18–21-year-old students in rural Wisconsin, and their results indicated issues related to transition planning which included decreased funding and difficulties connecting to adult services. Again, rural students preparing for transition to post-school life experience a lack of community resources, such as job shadowing opportunities, to support efforts that are made by their schools. Cultural differences, including values, communication styles, and learning styles between educators and the local community, can impact transition negatively (Anderson, 2012).

Recommendations for Best Practice in Rural Areas

Promising practices for transition services are based on research-based interventions and use evidence-based student development practices for improving transition outcomes. Replication of evidence-based practices in rural areas offers potential to enhance transition services. Transition services for individuals with disabilities are a necessity and expectation for adolescents during their secondary education process. Although necessary transition services have been well documented in the literature, those interventions may be challenging in rural communities. One of the most widely accepted services during the transition period is paid work experience. The literature is clear that if an individual has a work history while in high school, then students' employment options are significantly enhanced (Morris & Goodman, 2013). Rural communities are a tight-knit group who are familiar with each other, which makes demand-side job placement quite effective. Rural communities have the opportunity to intimately get to know potential employers and develop effective working relationships, which has the potential to result in more placement opportunities. Another promising practice relating to transition in rural communities is the creation of business advisory boards whose members participate in quarterly job meetings in the local high school (Hendrickson, Carson, Woods-Groves, Mendenhall, & Scheidecker, 2013). The purpose of these meetings is to allow potential employers to meet with students to answer questions about available opportunities and to begin to establish effective working relationship. This allows students to begin to learn what types of jobs are available and what the various requirements are.

Other recommendations are more specific to promoting students' self-determination and self-advocacy. A lack of administrative support and limited resources often lead to student self-determination programs that are limited to individual classrooms and teachers who are dedicated to do whatever they can to further their students' self-determination (National Center on Secondary Education and Transition, 2004). Thus, the following recommendations are made: (a) provide opportunities for decision-making starting early in life and encourage children to make informed choice through their lifespan; (b) begin self-determination instruction early in elementary grades and intensify specific skills during high school; (c) promote development and use of self-advocacy skills, focusing on an internal locus of control; (d) make work-based, self-directed learning and career exploration opportunities available to all students; and (e) incorporate self-determination and career development skills in the general curriculum (National Center on Secondary Education and Transition, 2004). Although these recommendations apply to students with disabilities in urban as well as rural areas, rural areas should have a heightened awareness of them.

Professional and Training Opportunities

Collaboration of transition planning would make transition process effective (Grigal, Test, Beattie, & Wood, 1997). The use of an asynchronous transition seminar series for professional development may be advantageous in rural areas where geography and accessibility may be a barrier. This series has been shown to increase the knowledge base and the ability to implement best practices and allows for the development of meaningful collaborative relationship with rural colleagues across the country. Frequently, professionals working in rural communities feel isolated and lack the opportunities for collaboration afforded to their urban counterparts.

In addition, self-determination and community-based education must be included as best practices in transition (Rouleau, 2012).

Parent Participation and Education

Lastly, due to the importance of family in many rural communities, having family members attend IEP meetings is critical. This type of involvement can significantly affect the student's outcomes and affords counselors and educators the opportunity to learn more about the student and their supports. Transition is important for students who have a disability. Effective collaboration in any transition setting is paramount. Ensuring effective communication with parents by using their preferred mode of communication (e.g., email, phone call, letter, and face-to-face meetings) will help to ensure reliable information dissemination. Providing thorough information and contact informational resources to individuals responsible for implementing various parts of the transition plan is vital for parents to follow up. Many individuals with disabilities receive financial supports, therefore educating parents and young adults on social security work incentives and transition services provided by other government/state and nonprofit agencies.

Parents should be familiar with the domains of adulthood to be addressed during transition planning: postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and community participation (Center for Parent Information and Resources, 2016). It may be helpful for parents to complete the *Parent Transition Survey* (Fournier, 2014), even if only as a way to help them identify important information. Finally, parents should be aware that educating themselves about transition and post-transition (adult) services is an ongoing process.

Summary

Transition planning serves to help prepare young adults with disabilities for postsecondary life. This process includes an interagency and collaborative relationship with the goal of providing young adults with disabilities a pathway and full access to participation in vocational, independent living, and postsecondary education opportunities. Individuals living in rural areas experience certain challenges which impact the rehabilitation process, e.g., lack of resources, qualified professionals, and financial capacity to name a few. By incorporating families in the transition plan, it helps them to acknowledge their role as experts of their child's abilities and strengthens their resources in providing support for their child. Educators, counselors, and case managers should provide innovative quality transition services for young adults with disabilities as mandated by the IDEA and allow them the ability to learn needed skills in the most restricted and age-appropriate environments.

Resources

Center for Rural Education: http://www.ed.gov/rural-education

Condon, E., & Brown, K. (nd). Planning for your transition from high school to adult life: A workbook to help you decide what you want your life to look like after graduation: http://ruralinstitute.umt.edu/transition/Articles/PlanningWorkbook.pdf

National Rural Education Center: http://www.nrea.net/

Navigating Resources for Rural Schools http://nces.ed.gov/surveys/ruraled/

Rural School and Community Trust: http://www.ruraledu.org

Transition of Students with Disabilities to Postsecondary Education: A Guide for High School Educators (first published March 2007. Reprinted March 2011).

Transition Services for Students with Disabilities: An Administrator's Guide: www.kings.k12.ca.us/SELPA/SecondaryTransitionResources/1-TransitionMaterialsforProgram

Learning Exercises
Self-Check Questions

1. What is the purpose of the individual transition plan?
2. Who should be on the transition planning team?
3. What are the barriers to transition planning and services for students with disabilities in rural areas?
4. What community service agents may be incorporated into an individualized transition plan?
5. What are the categories of transition services?

Experiential Exercise

1. Develop an individual transition plan for a transition student with autism spectrum disorder living in a rural area. Be sure to identify key services and timeline for delivery of services.
2. Interview a special education teacher, a special education coordinator, or rehabilitation

counselor to survey their perspective on transition planning and services for students with disabilities in rural communities.

3. Interview a parent of a child with a disability to obtain their perspective/experience of the transition planning process.

Multiple-Choice Questions

1. Which of the following is the most recent reauthorization of the IDEA Act?
   (a) 1997
   (b) 2012
   (c) 2000
   (d) 2004
2. The transition planning process for individuals with disabilities should begin at what age?
   (a) 12
   (b) 8
   (c) 21
   (d) 16
3. Which of the following composition makes up the transition team?
   (a) Educators, friends and family, and fellow classmates
   (b) Educators, counselors, and legislators
   (c) Educators, counselors, service professionals, and parents
   (d) None of the above
4. Which of the following are barriers to transition in rural areas?
   (a) Too many qualified professionals in special education to fill positions and as a result having to migrate to areas where opportunities are more favorable.
   (b) Few qualified professionals in special education and teachers having to teach beyond their expertise.
   (c) Not many accessible transportation and as a result having to rely on family for support is often met with reluctance.
   (d) Students in rural areas have unlimited access to resources but are not motivated to work toward transition goals.
5. Are parents experts of their own child as it relates to transition planning?
   (a) Yes, parents are experts of their own children and should be incorporated into all aspects of the transition planning process.
   (b) Yes, they should be included in the transition planning process for the first meeting but not included in subsequent meetings.
   (c) Yes, parents are only experts at home life activities and their opinions are only valuable in planning independent living goals.
   (d) Yes, but only special education professionals are experts of their child outside of the home setting.
6. ITP stands for which of the following?
   (a) Individual transition plan
   (b) Initialized training program
   (c) Independent training plan
   (d) Intervention transition plan
7. Which of the following are goals of a transition plan?
   (a) Independent living skills training only
   (b) Vocational training and postsecondary education
   (c) Complete high school with the goal of working in a sheltered workshop
   (d) Parenting skills and homemaking skills only
8. What role are parents considered to play once a young adult with a disability graduates from high school?
   (a) Continue in their parental role but do not participate in transition activities after graduation.
   (b) Continue to be a support system for their child by being an advocate for inclusive services.
   (c) Parents continue to lobby to have their child stay longer in school instead of graduating high school.
   (d) Parents are responsible for themselves and have done enough for their child upon graduation from high school.
9. Which of the following best describes benefit of participating in a family and or child support group?
   (a) Is beneficial for the family and or child
   (b) Is only helpful if there is a crisis

   (c) Cannot help with connecting to community resources
   (d) Is the only resource a child or parent need in the transition process
10. Transition planning is an individualized process that is determined based on the child's:
   (a) Goals and needs and starts at age 16.
   (b) Goals and needs lasting no more than 2 months
   (c) Goals and needs, however, the teacher's needs are more important than those of the child
   (d) Goals and needs and continues into a child's elderly years

Key

1. D
2. D
3. C
4. C
5. A
6. A
7. B
8. B
9. A
10. A

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11

Women, Older Adult, and LGBTQ Populations with Disabilities in Rural, Frontier, and Territory Communities

Debra A. Harley and Pamela B. Teaster

Overview

In this chapter our discussion of women, older adults, and LGBTQ persons with disabilities represents populations who once occupied positions of anonymity and exclusion and who, thanks to changes in law, attitudes, and understanding, are growing in numbers and visibility in the United States. As distinctly separate populations and as individuals with membership in multiple groups and with intersecting identities, women, older adults, and LGBTQ persons with disabilities have gained political attention that not only specify but, to a certain extent, mandate equal attention and inclusion in policy development, program implementation, and service delivery. Yet, persons belonging to each of these groups in rural regions must contend with the impact of a disability compounded by societal attitudes, stereotypes and biases, limited availability of services, and, frequently, inaccessible infrastructures. In addition, those groups share a high prevalence rate of poverty, mistreatment, victimization, and violence (Balsam & D'Augelli, 2006; Fredriksen-Goldsen et al., 2012; Teaster & Sokan, 2016). For those groups in rural communities, the urgency of attention to their unique challenges cannot be understated. Numerically, 2/3 of the 3142 counties in the United States are rural (Hartman & Weierbach, 2013), and almost 3 out of 10 Americans live in a rural, frontier, territory (RFT) community, or small town (US Census Bureau, 2010a). Approximately 62% of women with disabilities ages 16–64 are reported to have an employment-related disability (US Census Bureau, 2010b). Consistently, research implicitly and explicitly suggests that women and women with disabilities in rural regions have a triple disadvantage (i.e., gender, disability, rurality) that results in both employment and economic inequities (Carstensen, 2008; Hess et al., 2015; Son, Dyk, Bauer, & Katras, 2011; US Department of Agriculture, 2012).

In 2013, the number of females in the United States numbered 161 million, and the number of males was 156.1 million. The elderly population at age 85 and older consisted of 4 million females and 2 million males (http://www.census.gov/topics/population/age-and-sex/about.html). It is estimated that approximately 10% of the US population is LGBTQ (Carary, 2012). Ascertaining the number of LGBTQ persons living in rural areas is difficult because of a lack of willingness to self-disclose out of fear, discrimination, and stereotypes. However, many LGBTQ persons live in rural communities and face unique challenges, including access to inadequate, yet sorely needed services. A subgroup among

D.A. Harley (✉)
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: dharl00@email.uky.edu

P.B. Teaster
Center for Gerontology (0555), Virginia Tech University, Blacksburg, VA, USA

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LGBTQ persons in rural areas is LGBTQ adolescents who face gender identity and gender expression issues of biased language, harassment, assault, and safety challenges in school (Palmer, Kosciw, & Bartkiewicz, 2012). LGBTQ youth are reported to be at higher risk for mental (e.g., post-traumatic stress disorder, major depression, substance abuse, suicide attempts) (Kim, 2009; Quintana & Rosenthal, 2010) or physical health issues (Duke, 2011). Contrary to the commonly held belief that urban schools are more violent or more dangerous than schools in other areas, in fact, most often, rural schools may pose the greatest threats for LGBTQ students (Kosciw, Greytk, Bartkiewicz, Boesen, & Palmer, 2012). Also, rural areas have a higher percentage of older adults than the rest of the United States and are expected to experience a significant increase in this age group because many rural areas are becoming retirement communities while younger members out-migrate for job opportunities. Similarly, both women with disabilities and older persons with disabilities compose a substantial proportion of residents in rural areas. These shifts in population growth underscore the need for those populations to be critically evaluated, particularly when the predominant focus of service delivery seems to mirror the traditional and normative standard of male, young, heterosexual, and urban dwelling.

The purpose of this chapter is to contextually examine gender, age, and gender and sexual minority identity with regard to the limited availability of services in rural areas; issues of accessibility; community barriers, including community values and beliefs: stereotyping by service providers; and the interplay of gender, age, and gender identity; gender expression; and the influence of rurality for persons with disabilities. Information is also presented on a profile of women, older adults, and LGBTQ populations with disabilities in RFT communities.

Learning Objectives

By the end of the chapter, the reader should be able to:

1. Identify characteristics specific to women, older adults, and LGBTQ populations in rural areas.
2. Identify cultural influences in rural areas on women, older adults, and LGBTQ populations.
3. Understand the unique challenges to service provision for women, older adults, and LGBT persons in rural regions.
4. Understand the intersection of disability with gender, age, and gender identity and sexual expression in rural communities.
5. Identify strategies to improve service delivery to women, older adults, and LGBTQ populations in rural, frontier, and territory communities.

Introduction

In rural, frontier, and territory (RFT) regions, difficulties often outweigh opportunities for persons with disabilities, especially women, older adults, and LGBTQ populations. Each of those groups faces complex barriers in obtaining adequate services in healthcare, housing, independent living, community integration, education, and various other support services and in achieving success in employment, financial independence and economic security, and other accommodations. Differences in impairment rates in rural and urban areas illustrate consistent disparities across type of disability, suggesting a systematic relationship between impairment rates and geography highlighting higher rates among rural residents (von Reichert, Greiman, & Myers, 2014).

Data from the Rehabilitation Services Administration (RSA), known as RSA-911, include consumer characteristics, services provided, and employment outcomes of all case closures from vocational rehabilitation (VR) agencies annually. Ipsen, Swicegood, Colling, Rigles, and Asp (2014) examined RSA-911 data for 2008 and 2009 with demographic indicators for service outcome differences based on rural and urban locations. Overwhelmingly, the majority (74%) of VR cases originate in urban locations compared to 14% in large rural, 7% in small rural, and 5% in isolated rural areas. Further examination reveals that across these geographic areas, more males than females receive VR services: those ages 16–19, 35–44, and 45–54 comprise the larger number of cases; the majority are White, have less than a high school education or are high school graduates, and have mental or physical disabilities. In fact, urban residents had higher rates of primary mental disability compared to each rural region (large rural 33%, small rural 29%, isolated rural 24%), and each rural region (large 30%, small 29%, isolated 24%) had higher rates of physical disability as compared to urban (25%). Persons in large rural (13%), small rural (16%), and isolated rural (19%) areas exhibited higher rates of learning disabilities than did urban residents (14%). Women account for 43% of VR cases in urban areas and 45% each in large, small, and isolated rural communities. Persons age 55 and over represent the smallest percentage of cases in urban (10%) and rural (10–11%) areas. Visual (4%) and sensory (7–8%) make of the lowest percentage of disabilities across all geographic areas. In addition, persons receiving social security benefits (Social Security Disability Income [SSDI] or Supplemental Security Income [SSI]) had low employment outcomes (12–15% for urban and rural). Finally, regardless of geography, VR consumers received assessment proportionately (52–57%), with isolated areas receiving the highest percentage, diagnosis and treatment (25–29%), and counseling and guidance (40–43%). Of other comparative services received, VR consumers in rural areas (18–22%) received fewer services in job placement assistance compared to urban areas (21%) and in transportation (16% vs. 24%). These data suggest that rural VR consumers received fewer dollars of purchased services (Ipsen et al., 2014).

In general, population and geographic challenges of RFT communities present significant barriers for VR service providers. The provision of services to women, older adults, and LGBTQ populations is further complicated by attitudes, beliefs, and cultural attributes in RFT communities, which are discussed later in the chapter. Women, older adults, and LGBTQ populations with disabilities each face many of the same psychosocial, economic, and health concerns and issues of their counterparts in urban areas, but their status and access to services are affected even more by the social context within which they experience their disability. Disability encompasses not only the physical or mental conditions that affect the body and mind but also the ways in which geographic, social, cultural, and physical environments create obstacles to persons with disabilities (PWDs), especially in RFT communities (Enza & Enza, 2002). Rural residents are greatly influenced by geography, and so is their health, whether by the physical terrain of their environment or the composition of their communities (Crosby, Wendel, Vanderpool, & Casey, 2012). See Research Box 11.1 for barriers to primary care in a two-state study by Iezzoni, Killeen, and O’Day (2006).

Research Box 11.1

See Iezzoni et al. (2006).

Objective: To learn about the healthcare experiences of rural residents with disabilities.

Study Setting: Rural areas in Massachusetts and Virginia.

Research Design: Adults with sensory, physical, or psychiatric disabilities were recruited through local centers for independent living to participate in focus group interviews.

Data Collection Methods: Verbatim transcripts of interviews were reviewed to identify major themes.

Results: Interviewees described the impediments to healthcare in rural America; disability appears to exacerbate these barriers. They reported substantial difficulties finding physicians who understand their disabilities and sometimes feel that they must teach their local doctors about their underlying conditions. Interviewees described needing travel periodically to large medical centers to get necessary specialty care. Many are poor and are either uninsured or have Medicaid coverage, complicating their searches for willing primary care physicians. Because many cannot drive, they face great difficulties getting to their local doctor and especially making long trips to urban centers. Available public transportation often is inaccessible and unreliable. Physicians; offices are sometimes located in old buildings that do not have accessible entrances or equipment. Based on their personal experiences, interviewees perceive that rural areas are generally less sensitive to disability access issues than urban areas.

Conclusions: Meeting the healthcare needs of rural residents with disabilities will require interventions beyond healthcare, involving transportation and access issues more broadly.

A Profile of Women with Disabilities in Rural Regions

As a group, women have a life expectancy that is notably longer than that for men, but they also have a higher incidence of disability and spend a greater proportion of their later years with significant disability and decline in functional status (Laditka, Laditka, Olatosi, & Elder, 2005; Murtagh & Hubert, 2004). Moreover, women with disabilities are less likely to receive clinical preventive services (Wei, Findley, & Sambamoorthi, 2006). In our discussion of women in rural communities, we acknowledge that rural women are not a homogenous group; they are diverse in demographics, socioeconomic status, geography, and development. However, rural women share certain characteristics (e.g., distance, lack of transportation, geographic barriers, inadequate funding of services, poverty, stressful life events) that contribute to health and well-being as well as susceptibility to illness, disability, and outcome of treatment (Coward et al., 2005; Mulder et al., 2000). Rural women with disabilities represent a high-risk group (Harper, 2001; Thurston, Leach, & Leipert, 2012) and tend to be poorer, in worse health, less educated, and more dependent on government programs than their urban counterparts (Szalda-Petree, Seekins, & Innes, 2000; US Department of Health and Human Services et al., 2013). In fact, rural women with disabilities are aptly referred to as the poorest of the poor (Mulder et al.). Significantly, the lower employment rate of women with disabilities most likely contributes to differences in poverty rates (O'Day & Foley, 2008). Further, rural areas have some of the greatest incidences of poverty (Housing Assistance Council, 2012), with remote places exhibiting the greatest disadvantage (Weber, 2007). Rural poverty rates are on the rise, while urban poverty rates are declining (US Department of Agriculture, 2013). See Chap. 2 for additional information on rural poverty.

Ethnicity

Ethnic minority women make up a substantial portion of rural women. According to the US Department of Agriculture (2010), more than 3.7 million women in rural America self-identify as African-American, Hispanic/Latino, or American Indian. As a group, African-Americans have a shorter life expectancy and higher rates of disability than Whites, Latinos, and Asians, and Latinos have a higher life expectancy than Whites. African-American women live a greater percentage of their lives with disability than their male counterparts. African-American women develop functional health challenges earlier than their White counterparts. In general, African-American women experience stress and health disadvantages related to an interaction and multiplicative effects of race, gender, class, and age (Lekan, 2009).

Aging White men appear to have the least disabling limitation on average, but increase slightly until age 75. Latino-American women have on average twice as many physical limitations as do White men. Latino-American men, African-American men, White men, and White women tend not to vary significantly in the rate in which they develop disabilities as they age; however, African-American women gain more disabilities early on. After their mid-60s, the rate of disabilities begins to decrease for African-American women, and by age 75 the pace of acquiring disabilities stabilize (Warner & Brown, 2011) (See Chaps. 9 and 13 for further discussion of disability and ethnic minorities). Warner and Brown found that life disadvantages such as lower income and lack of access to healthcare surfacing in midlife tend to follow individuals throughout their lives and that women are particularly at risk for such disadvantages. The emergence of physical limitations and disability with the intersection of race/ethnicity, gender, and age illuminates the need for further research and interventions that address the unique health experiences of women, especially African-American women as they age.

Mental Health Risk and Protective Factors

Women with disabilities who live in rural, frontier, and territory areas experience environmental risk factors that increase their propensity for disabilities, especially depression. Environmental factors include unemployment, poverty, exposure to abuse and violence, poorer health, less education, greater dependence on government programs, and other life stressors (Hughes & University of Montana Rural Institute, 2007). It is estimated that five million adult women living in RFT regions are age 65 years and older, and more than four million are identified as having a disability (US Census Bureau, 2010b, c). In addition, women with disabilities in RFT areas face two additional risks for depression: having a disability and living in rural areas. Moreover, barriers to accessing mental health services are more pervasive in RFT areas in which 60% of rural residents live in areas with a shortage of available and qualified mental health professionals (US Department of Health and Human Services, 2012). Access to mental health services is further exacerbated by transportation problems, a lack of mental health service providers, an overburdened healthcare system, stigma, geographic location, inadequately funded mental health services, and concerns about confidentiality because of the social closeness of small communities (Hughes & University of Montana Rural Institute, 2007; Sawyer, Gale, & Lambert, 2006). See Chap. 26 for an in-depth discussion on mental health.

In general, women are twice as likely as men to have depression. Gender differences occur, particularly in the rates of common mental disorders, including depression, anxiety, and somatic complaints, in which women predominate and may be more persistent in women than men (World Health Organization [WHO], n.d.). In addition, risk factors such as gender-based roles, stressors, negative life experiences and events, gender-based violence, socioeconomic disadvantage and income inequality, low or subordinate social status and rank, advanced age, low education levels, limited employment opportunities, and being unmarried create susceptibilities to depression, to which rural women may be especially vulnerable (Farr, Bitsko, Hayes, & Dietz, 2010; WHO). Explanations for the disparities of mental health issues in rural areas include that RFT residents are less likely to receive treatment at all, as well as barriers such as the cost of treatment, lack of awareness of mental illness, distrust of mental health services, disbelief in a need for treatment, lack of awareness of where to access services, stigma, lack of time to dedicate to treatment, lack of insurance, and lack of anonymity in RFT communities (Talbot & Coburn, 2013). Disproportionately, rural women with physical disabilities exhibit moderate to severe depression and higher than average thoughts of suicide. Among rural women with physical disabilities, those at greater risk for depression are younger, have greater problems with pain, have more limited mobility, and are less satisfied with their social network (Hughes, Nosek, & Roberson-Whelen, 2007).

Research suggests that mental health issues and escalating substance use problems affect women to a greater extent than men across different countries and different settings (WHO, nd). Gender bias in diagnosis and treatment of mental health disorders further disadvantage women in help-seeking behaviors. Women tend to seek help and disclose mental health problems to their primary healthcare physician, while men are more likely to seek help from a specialist in mental healthcare. Men are also the principal users of inpatient care. Gender stereotyping about proneness to emotional problems in women and alcohol problems in men reinforce social stigma and constrain help seeking along stereotypical lines (WHO). Women who entered treatment for substance abuse were significantly less likely than men to complete treatment (Agency for Healthcare Research and Quality, 2011). These barriers are magnified in rural communities that often ascribe to traditional gender role expectations and values regarding behavior. Often, healthcare providers in rural areas are also influenced by these stereotypical beliefs. Clearly, the complexities of gender bias in conjunction with some rural cultural beliefs increase the vulnerability and victimization of women.

Other research shows that some aspects of RFT life may offer protective factors against mental health issues for women. On the one hand, the rural nature of the environment plays an important role in increasing the demands for self-reliance and necessity to perform a wide range of life-supporting activities for oneself. On the other hand, interdependence and good relationships with neighbors are essential in the rural environment as precursors to social support and assistance in daily RFT living (Comerford, Henson-Stroud, Sionainn & Wheeler, 2004). For example, women who live on farms scored higher than average on mental health assessments than their urban dwelling counterparts (Hillemeier, Weisman, Chase, & Dyer, 2008). Dorfman, Mendez, and Osterhaus (2009) found that in response to economic hardship, disruption of family life, and fears, uncertainties, and stressors associated with the Great Depression and wars of the twentieth century, older rural women demonstrated resilience through frugality, reliance on social supports, and acceptance. Rural residents have long been known for their resilience in dealing with economic hardship, expressing differential social outlets, and exhibiting a certain kind of grittiness. The general concept is that resilience is primarily explained as an attitude toward life, and resilient people are able to make adjustments to life changes (Gray & Gash, 2014; McManus et al., 2011). (See Chap. 7 for a more in-depth discussion on resilience and strength of rural residents.) Wells (2010) conducted a study of older adults to determine if resilience levels vary depending on rural, urban, or suburban location and if the relationships of sociodemo-

Research Box 11.2

See Wells, M. (2010).

Objective: The purpose was twofold. First, to determine if resilience levels vary in older adults living in rural, urban, or suburban areas. Second, to determine if the relationships of sociodemographic factors (age, income, education, marital and employment status), social networks, health status, and resilience vary with the location in which older adults live.

Research Method: A cross-sectional design was used to collect data from 277 registered voters aged 65 years or over who lived in rural, suburban, or urban locations in New York State. The instruments used were the Resilience Scale, the SF-12v2, and the Lubben Social Network Scale-revised.

Results: No differences were found in resilience levels across the three locations. In regression analysis, stronger family networks, lower household income, and good mental and physical health status were found to be significantly associated with higher resilience levels.

Conclusion: The location in which older adults reside did not affect resilience levels. Strong ties and good mental and physical health were associated with resilience. Finding an association between resilience and low income was unexpected. Mental health status was most strongly associated with resilience. Although more research is needed, screening older adults for resilience levels and intervening when low levels are identified by implementing strategies to build resilience may be clinically relevant.

graphic, social networks, physical and mental health status, and resilience vary according to the location in which older adults live. Wells found no differences in resilience levels across the three locations, and certain characteristics were found to be associated with high resilience levels. See Research Box 11.2.

Susceptibility to Violence

Among women with disabilities, older adults and women with intellectual and developmental disabilities (IDD) experience disproportionate rates of abuse (Hollomotz, 2011). Research suggests that the extent of abuse is a problem of crisis proportion for women in small rural and isolated areas as compared to urban women (Peek-Asa et al., 2011). Peek-Asa et al. (2011) found that the prevalence, frequency, and severity of domestic violence differ by rurality and geographic access to resources. Specifically, rural women reported a significantly higher severity of physical abuse than their urban counterparts. The average distance to the nearest domestic violence resource is three times greater for rural women, and rural domestic violence programs served more counties and had fewer on-site shelter services. Women in small rural and isolated areas live more than 40 miles from the closest programs compared to less than 1% of women living in urban areas.

In particular, women with disabilities in rural and urban areas encounter unique vulnerabilities beyond those experienced by women in general including physical, emotional, and sexual abuse by caregivers, abandonment, voyeurism, and extortion (Nosek & Howland, 1998; Powers, Hughes, & Lund, 2011; Smith & Strauser, 2008). Additional forms of disability-specific violence include destruction of medical equipment and communication devices, physical neglect withholding, stealing or overdosing of medications, and financial abuse (Curry, Powers, Oschwald, & Saxton, 2004; Nosek, Foley, Hughes, & Howland, 2001). Maltreatment by personal care assistants and other service providers is a unique problem facing women with disabilities (Nannini, 2006; Nosek, Howland, Ritala, Young, & Chanpong, 2001; Saxton et al., 2006). Moreover, women with disabilities who have been abused physically and sexually have higher levels of unemployment than do women without disabilities that have not been abused (Nosek, Hughes, Taylor, & Taylor, 2006; Powers, Hughes, & Lund, 2011; Smith & Strauser).

Rural women experience higher rates of domestic violence or intimate partner violence (IPV) with greater frequency and severity of abuse than their urban counterparts. IPV is different from domestic violence in that the perpetrators include spouses and other domestic partners. Some research suggests that social and geographic isolation may be a contributing factor to the rates and severity of IPV (Breiding, Ziembroski, & Black, 2009; Peek-Asa et al., 2011). Peek-Asa et al. found that 61.5% of isolated rural women reported four or more events of physical violence in the past year as compared with 39.3% of urban women, and more than 30% reported severe to very severe physical violence compared to 10% of urban women. The effects of violence on women produce adverse immediate and short- and long-term physical and psychological health outcomes (Hassouneh-Phillips McNeff, Powers, & Curry, 2005). Frequently, injury as a result of IPV may result in disability. Weeks, Macquarrie, Begley, Gill, and Leblanc (2016) suggest that increased efforts are needed in improving both public and professional education regarding older rural women and IPV.

Although this chapter is focused in part on women, we would be remiss not to mention that men with disabilities, especially developmental, intellectual, and physical disabilities, are as likely as their female counterparts to be victims of sexual abuse (Powers et al., 2011). Powers et al. (2011) indicated that unlike women, men are more likely to be abused by female caregivers, with the abuse producing negative consequences across their lives, including an impediment to employment and a barrier to self-care and to living independently. Compared to men without disabilities, men with intellectual disabilities were more likely to report caregivers manipulating their medications; they are more likely to report being held against their will and being hit, kicked, slapped, or hurt.

Employment

In general, women with disabilities have higher rates of unemployment compared to women without disabilities, with African-American women with disabilities having the lowest odds of employment (Oberoi, Balcazar, Suarez-Balcazar, Langi, & Lukyanova, 2015; Smith & Alston, 2008). Women with disabilities are more likely than women without disabilities to be employed in the service sector (e.g., food preparation, building and grounds maintenance, medical assistant, personal care). In addition, women with disabilities participate in blue color occupations at higher rates than do women without disabilities and are less likely to be in professional or technical occupations. Overwhelmingly, women with disabilities are clustered in service sector occupations, which often are part-time, the lowest paid, and the least likely to offer health insurance and other benefits (O'Day & Foley, 2008). The role of work in the lives of women is highly correlated not only with economic independence but also with self-concept and social and psychological well-being (Chung & Rubin, 2008).

Additionally, rural women experience complicated challenges in obtaining productive employment that pays a livable wage. Challenges include transportation and under-availability of support services, with persistent and inadequate advocacy skills for women with disabilities in rural communities in each rural geographic region (Carstensen 2008; Parent, 2008). In addition, rural low-income mothers are more vulnerable as compared to their urban counterparts under the current welfare policy, which has a work-first approach (Son et al., 2011). Son et al. argue that the lower level of education, lack of affordable child care, lack of transportation, and time and emotional demands from family members influence three employment trajectories for rural women: continuous employment, intermittent employment, and stable employment. Women with disabilities in rural areas who access assistance despite the barriers do so with a tenacity iconic of rural living by connecting with the strong social network of small town living. Unfortunately, women who are not part of the interconnectedness of the community remain isolated with their needs unmet (Carstensen).

Carstensen (2008) suggests two areas on which to focus to strengthening employment outcomes for rural women with disabilities. One area is to build partnerships between community services, schools, businesses, self-advocacy and other organizations, and transportation and mobility management (i.e., coordinated mobility). In addition, partnerships between schools and service providers can provide training that increases the use of technology by women with disabilities, in turn changing ways in which rural women access work and compete in the global market (Carstensen). Another area is to capitalize on existing personal or social networks in rural communities and turn them into employment networks so that through social networking, employment can be customized (e.g., job carving, job shaping, flexible schedule) for rural women with disabilities, and employers are more acceptable to such an arrangement when they and the employee have established a relationship. Rural communities provide an advantage because of the "natural opportunity to interact with the same people on a recurring basis and build relationships" (Carstensen, 2008, p. 13). Many of these relationships are life-long ones.

A Profile of Elders with Disabilities in Rural Regions

In general, "increasing life expectancy is one of the greatest public health achievements of the twentieth century" and "has made disability a linchpin for understanding healthcare resource needs" (Laditka et al., 2005, p. 1). Education is considered as a moderating factor in life expectancy. Individuals with more education live longer, healthier lives than those with less education (Hummer & Hernandez, 2013; Montez 2012). Education may confer protective effects relating to specific disability, functional limitations, and major diseases for several reasons. First, education may influence an individual's ability to understand risks to health or the propensity to accept or reduce known risks (Fries, 2002; Laditka et al.). Second, education may alter health behavior (e.g., smoking, taking vitamin supplements, better diet, exercise). Finally, education is associated with cognitive functioning, which helps individuals develop higher-order cognitive skills to live healthy and long lives (Baker et al., 2011).

Population aging is a worldwide phenomenon, especially in developed countries (Krout & Hash, 2015). Of the over 40 million people aged 65 and over in the United States (13% of the population), about 15 million (38%) report having one or more disabilities. The oldest-old (age 85 and over) represents the highest percentage of disability in the older population. Women composed a higher percentage of disability (59%) than their older male counterparts (56.8%) (He & Larsen, 2014). Although the majority of older people do not live in rural areas, older adults make up a disproportionate percentage of rural populations (Glasgow & Brown, 2012; Krout & Hash, 2015), with residents aged 65 and older accounting for approximately 15% of the RFT population (United States Administration on Aging, 2007). Glasgow and Brown describe rural aging populations in the United States in two contrasting contexts: (a) areas experiencing natural population decrease (i.e., more deaths than births) and (b) areas experiencing relatively high rates of net in-migration at older ages. Although natural population decreases occur, the phenomenon is geographically concentrated in the United States and characterizes particular regions (i.e., the Great Plains, Western Corn Belt, upper Midwest, and the Appalachian spine from western Pennsylvania through North Carolina). Net in-migration of older ages is concentrated in the South and Southwest (i.e., Ozark Ouachita Plateau of Missouri and north Arkansas, the Upper Great lakes, the Front Range of the Rocky Mountains, and southern Appalachia, especially in North Carolina and Tennessee) (Glasgow & Brown, 2012).

Growth in the US population aged 65 and older will increase exponentially between 2010 and 2030, with baby boomers (persons born between 1946 and 1964) representing a vastly larger portion. Although aging baby boomers will affect both urban and rural areas, its impact is predicted to be especially dramatic for rural areas (Glasgow & Brown, 2012) because older migrants are disproportionately likely to move to rural areas (Brown & Glasgow, 2008). Baby boomers in the United States are also more likely than the previous generation to have a disability as they approach late life. Although baby boomers are living longer than people approximately 20 years older, boomers are not necessarily healthier. King, Matheson, Chirina, Shankar, and Broman-Fulks (2013) found that despite their longer life expectancy over previous generations, baby boomers have higher rates of chronic disease, more disability, and lower self-rated health than members of the previous generation at the same age. Baby boomers have increased rates of obesity, hypertension, diabetes, and hypercholesterolemia, despite lower rates of smoking, emphysema, and myocardial infarction (King et al., 2013; Martin & Schoeni, 2012).

Increasingly, as the population ages, planning services to help in the transition from full health to levels of disability such that older people can live in their communities is essential for their residence in rural areas (Laditka et al., 2005; Redfoot, Feinberg, & Houser, 2013). Particularly relevant to older populations are the health penalties and health advantages of living in rural versus urban areas, which in turn affect health status (see Table 11.1). Although some rural elders are healthy and socially active, many others are not. In general, urban areas offer the advantage of better access to and more cohesion with many necessities of life, even with the migration of the middle class to the suburbs (Vlahov, Galea, & Freudenberg, 2005). Montgomery, Stern, Cohen, and Reed (2003) suggest that the socioeconomic heterogeneity of cities may bring benefits of healthcare and education within reach of more disadvantaged urban residents. Several studies also found that not only do elderly residents in rural areas have

Table 11.1 Health penalty and health advantage of geographic location

Urban		Rural	
Health penalty	Health advantage	Health penalty	Health advantage
Air pollution	Better healthcare system	Limit access to healthcare/ facilities	Access to fresh food
Crime	Health-promoting environment (pools, gyms, facilities), access to wide variety of wholesome foods	Higher morbidity, higher disability rate, childhood risk factors	Less likely to relapse into depression or mental illness one recovered
Poor sanitary conditions	Access to public transportation	Increased riskfactors for substance abuse	Sense of community/ interdependence
Overcrowding	Proximity to wealth and poverty (service)	Higher poverty	Less daily stress from external factors
Decaying infrastructure	Sustained social organizations	Limited availability of rehabilitation	Long-lasting/more personal relationships
Excess morbidity and mortality	Political support for services	Less developed infrastructure	Easy access to natural world

Adapted from Combs (2006), Laditka et al. (2005), and Vlahov et al. (2005)

higher levels of morbidity but also that those in the Deep South have significantly higher rates of morbidity than those in the North (Hayward & Gorman, 2004; Lin, 2000; Porell & Miltiades, 2002). The greater risk for morbidity was attributed to the higher incidence of stroke and diabetes in the South, with exposure to risk factors early in life predisposing residents to disability later in life. Although both urban and rural living offers health advantages and disadvantages, urban areas may confer more advantages, and "the ultimate health status can be viewed as the sum of the urban advantages minus the sum of the penalties" (Vlahov et al., 2005, p. 4).

Disability rates in RFT regions are higher across all age groups, with noncore counties (nonmetropolitan counties with an urban core population of less than 10,000) experiencing the highest rates overall. Irrespective of age, RFT regions have higher more persons with higher rates of impairment (von Reichert et al., 2014), and coupled with that is that the most significant rural demographic characteristic connected with disability is poverty (Seekins & Associates, 2011). Elders living in poverty are less likely or less able to access healthcare and other support services (US Department of Health and Human Services, 2007). Warner and Brown (2011) found that the emerging patterns in the functional health of older adults were early life events, adult socioeconomic status, marital status, and health behaviors that explain disparities in the limitations men experienced, but as clearly for women. Disproportionately, low-income elderly people live in rural communities. Although the number of rural elderly and urban elderly people with Medicaid coverage is essentially equal (North Carolina Rural Health Research and Policy Analysis Center, 2009), the percentage is greater in rural areas where there is more reliance on nursing home care because of a lack of community-based alternatives (Rural Policy Research Institute, 2006). Moreover, insurance reimbursement levels for healthcare is a significant barrier for older rural residents because healthcare providers are often unwilling or unable to accept remuneration at such low levels (Iezzoni, Killeen, & O'Day, 2006).

Medicare beneficiaries make up 14% of the total US population. According to Cubanski, Huang, Damico, Jacobson, and Neuman (2010), 24% of all Medicare beneficiaries live in rural areas. Rural beneficiaries comprise more than 50% of the Medicare population in Montana, Nebraska, North Dakota, Ohio, South Dakota, Vermont and Wyoming. A breakdown of the demographics of Medicare recipients reveals that they are predominantly White and female, and those over age 85 make up 12% of recipients. Overwhelmingly, rural Medicare recipients have limited incomes and face rising premiums and out-of-pocket costs for coverage, even though as 2015, the Affordable Care Act modified some Medigap (supplemental insurance) plans to include cost sharing for some services (Bennett, Lopes, Spencer, & van Hecke, 2013).

Ensuring the quality of life of a growing elderly population is considered one of the greatest challenges of the twenty-first century (Redfoot et al., 2013). This is particularly important for rural elders because their needs remain largely ignored, unaddressed, or not prioritized as part of socioeconomic and healthcare policy (Baernholdt, Yan, Hinton, Rose, & Mattos, 2012; Kumar, Acanfora, Hennessy, & Kalache, 2001). In fact, research identified priorities for action for rural older adults that include sustained access to prescriptions, transportation solutions, inadequate access to healthcare workers and facilities, lack of quality healthcare, poor infrastructure and coordination of services, scarce assisted living and in-home care for frail older adults, social isolation, financial constraints, and barriers related to culture, language, and economics (Averill, 2012; Baernholdt et al., 2012; Grymonpre & Hawranik, 2008; Xu & Borders, 2003). According to Iezzoni et al. (2006), "meeting the health care needs of rural resident with disabilities will require intervention beyond health care, involving transportation and access issues more broadly" (p. 1258). Refer to Research Box 11.1 for results of Iezzoni et al. study on barriers to obtaining primary care for rural residents with disabilities.

The intersection of age, gender, and poverty for rural residents requires further inspection. On average, women tend to live longer than men, and the ratio of women to men increases with age (United States Census Bureau, 2010d). Elderly rural women are more likely to have a disability, be widowed, older, and poorer than their urban and suburban counterparts. Older rural women experience more health issues that affect their ability to drive, hamper mobility, and compromise their quality of life than do older rural men. In addition, RFT areas lack many social and health services for older women such as primary care physicians, social workers, and caseworkers trained in gerontology and geriatrics (Bennett et al., 2013). The most common psychiatric diagnoses in older adults are depression, anxiety, substance abuse, and dementia; however, depression is not a normal part of aging (Hicken, Smith, Luptak, & Hill, 2013). Toner, Ferguson, & Sokal (2009) report that poor physical health can increase risk for mental illness, particularly depression and anxiety, in combined effect with bereavement, poor social support, and functional decline. More so than their urban counterparts, older rural adults admitted for substance abuse treatment were more likely to use alcohol and non-heroin opiates (Center for Behavioral Health Statistics and Quality, 2012). These psychiatric comorbidities occur in a context of limited access to care that greatly complicates effective management (Hicken et al.). Older adults living in rural areas are more likely than urban elders to report being less happy and having worse health. In addition, rural elders are more likely to be institutionalized than are urban elders due to an inability to care for themselves at home (Hutchison, Hawes, & Williams, 2004; Nelson & Gingerich, 2010). Other reports suggest that the rates of mental illness are similar between urban and rural areas, but suicide rates are higher in rural areas (The National Advisory Committee on Rural Health and Human Services, 2008). Yet, other studies suggest positive mental health outcomes for rural older adults in that they may have fewer depressive symptoms than non-rural residents. Ziembroski and Hauck (2004) found that rurality and regional residence might be a buffer against depression.

Elderly residents with disabilities living in rural communities must also contend with issues of mistreatment, and geographic isolation may exacerbate the problem, both in its intensity and due to availability of services. Abused elders living in rural areas may be living with physical disabilities and experiencing dementia and may be residing in community of facility settings. In a study of ten African-American rural North Carolina victims and six abusers, Griffin (1994) found that, while poverty was an underlying factor in all cases, financial exploitation was the most common type of mistreatment with abusers involved in dependent relationships with the older adults who were abused. Dimah and Dimah (2004) examined six forms of substantiated elder abuse among rural and urban women and found that more rural women experienced physical abuse, emotional abuse, and deprivation than their urban counterparts. Rural women were slightly (88% vs. 86%) more likely to accept services than were urban women. Using a threshold model of abuse, Stone and Bedard (2002) found that Canadian residents in smaller (rural areas) had a lower threshold for elder abuse than did respondents living in larger (urban areas).

Overall, understanding aging and older persons with disabilities in rural, frontier, and territory communities requires counselors and practitioners to consider that people do not age in a "spatial vacuum." That is, all people age somewhere, and the place of aging has an impact on people and vice versa (Krout & Hash, 2015). Rurality may be both a resiliency factor and a risk factor depending on certain circumstances. Older people with disabilities living in rural areas may continue to experience social, economic, and environmental conditions that threaten their health and perpetuate risks for disability, particularly for those aging in place, while much of the younger population moves away.

A Profile of LGBTQ Persons with Disabilities in Rural Regions

There is a dearth of systematic research and data on LGBTQ populations with disabilities nationally and even more so in rural communities. The information on prevalence of disability among LGBTQ person is based on the overall population and not necessarily specific to those in rural areas. Therefore, any discussion of LGBTQ persons in RFT communities should consider differences as well as commonalities among these groups in terms of health disparity and service needs. According to Disabled World (2015), lesbian, gay, and bisexual (LGB) adults have a higher prevalence of disability than do their heterosexual counterparts. Comparatively, 25% of heterosexual women, 36% of bisexual women, and 36% of lesbians and 22% of heterosexual men, 40% of bisexual men, and 26% of gay men experience a form of disability. Lesbians and bisexual women exhibit higher rates of smoking, frequent mental distress, arthritis, obesity, asthma, and poor physical health than heterosexual women. Gay and bisexual men are more likely to be smokers and experience frequent poor health and mental distress than heterosexual men, but they are less likely to be obese than heterosexual men. Even after controlling for variables of mental health, physical health, health behaviors, chronic health conditions, and sociodemographic characteristics, LGB adults demonstrated increased prevalence of disability when compared to their heterosexual counterparts. Moreover, the odds of LGB adults experiencing a disability is higher than their heterosexual counterparts of comparable age, even for those who are fairly young, suggesting the age of onset of disability might be lower in these populations (Disabled World). The diversity and subgroups (e.g., lesbians, transgender with sex reassignment) of these populations have different health risks and concerns that are not necessarily shared collectively.

Often, LGBTQ persons face the challenge of "a double coming out" – as a person with a disability and as LGBTQ (Fish, 2007, p. 3). In working with LGBTQ persons with disabilities, we must consider that they commonly face the dual challenge of actual discrimination and fear of discrimination when dealing with health and social service networks (Institute of Medicine, 2011; Lee & Quam, 2013). Thus, many LGBTQ persons with disabilities pass as heterosexual for health and social services because they fear being refused services or treated in a derogatory manner. The result of these high levels of distrust of healthcare providers and human/social service workers can prevent discussion about risk factors for certain kinds of health disorders and disabilities, which may worsen over time, resulting in additional functional limitations. Service providers' ignorance and insensitivity combine often to be as much of a barrier as the disability itself. Regardless of age, LGBTQ persons in RFT communities encounter two specific obstacles: homobi-trans-phobia and heterosexism. According to Brothers (2003), health and human/social service providers are so focused on attending to medical and functional requirements they neglect to take into account the personal and emotional needs and life experiences of LGBT persons with disabilities.

Overwhelmingly, LGBTQ identities have been studied in urban spaces in both cultural and personal understandings (Kazyak, 2011). Although some studies emphasize positive aspects of rural gay life (e.g., Gugliucci et al., 2013; Oswald & Culton, 2003; Rowan, Giunta, Grudowski, & Anderson, 2013; Wienke & Hill), most research suggests that negative aspects outweigh the positive (e.g., D'Augelli, 2006; Datti, 2012; Eliason & Hughes, 2004; Lee & Quam, 2013). Alternately, others indicate that LGBTQ persons in rural areas have better experiences with family ties and weaker ones with service delivery and civil rights (e.g., Oswald & Culton, 2003). In a study of counselors' attitudes in urban and rural settings about LGTB clients, Eliason and Hughes (2004) found that counselors from both settings had very little formal education regarding the needs of LGBT clients, and nearly half reported negative or ambivalent attitudes. Although urban counselors were more racially diverse and more likely to have grown up in an urban area, reported having considerably more contact with LGBT clients, and had more formal and continuing education about LGBT people than the rural counselors, urban counselors did not translate their knowledge nor experience into favorable perceptions. Ironically, the results suggest that urban counselors are no more knowledgeable of the needs of LGBT populations or are more accepting of LGBT persons than are rural counselors.

Rural communities are not typically seen as places compatible with the needs and wants of LGBTQ persons. The prevailing view is that sexual minorities are better off living in large cities (Wienke & Hill, 2013). LGBTQ persons' identities or behavior are perceived as undermining the culture in rural communities and considered a threat to social order; thus, sanctions are used to promote expulsion or conformity (Harley, 2016b; Harley, Stansbury, Nelson, & Espinosa, 2014). Many LGTBQ persons live in rural areas out of choice or necessity because their families have lived in their community for generations (kinship systems) or because they are migrant farm workers (National Center for Lesbian Rights, 2016, www.nclrights.org/pur-work/rural-communities/). For LGBTQ persons who migrate to urban areas and return to rural communities, the return can create high levels of stress (Oswald, 2002).

For instance, Wienke and Hill suggest that rural versus urban LGBTQ residence should be examined from four competing perspectives. The first is that rural life is less beneficial (e.g., social isolation, intolerance, limited supports) to LGBTQ persons' well-being than urban life. The second is that rural life is more beneficial (e.g., low cost of living, less stress, stronger social ties, and shared traditions) to LGBTQ persons' well-being than urban life. The third perspective is that any observed differences between rural and urban LGBTQ residents are attributed to differences between the two populations in terms of the composition of ethnic, age, family status, and other demographic characteristics, not due to the characteristics of the geographic setting. The final perspective suggests that any observed differences in well-being may reflect a selection process in which well-adjusted LGBTQ persons remain in the areas in which they were raised (nonmigration), and poorly adjusted persons move away (select migration).

In interviews with LGBTQ persons in rural areas, Kazyak (2011) suggests that an "artificial anonymity" emerges in which interviewees asserted that others do not explicitly recognize their sexual identity either positively or negatively. Visibility of LGTBQ persons in rural areas is tied to being seen with the same person at various places (e.g., bank, grocery store). Thus, others might know about and tacitly accept their sexual identity, which is attributed to the close-knit nature of rural life. In addition, interviewees describe the sense of anonymity that stems from the close-knit nature of rural life as tied to a sense of safety in which everyone knows and will continue to see them around, which lessens the opportunity to express the hostility that may happen in urban settings.

Although LGBTQ persons in rural areas face the same issues as their urban counterparts (bias, rejection, stigma), these issues are accentuated by the lack of a visible gay community, social isolation, an overall lack of LGBTQ-specific services and resources, a more conservative political climate with an emphasis on fundamentalist religious beliefs, and cultural values endemic to RFT communities (Harley, 2016a; Hastings & Hoover-Thompson, 2011), as well as political and economic inequities between rural and urban areas (Comerford et al., 2004) and challenges for persons with disabilities in general. In addition, community closeness and interdependence in RFT areas often blur boundaries of privacy and result in information being shared through local venues and throughout the community (Harley, 2016a). LGBTQ persons have lower levels of openness and "outness" and higher levels of guardedness with people, including family relationships and close friends (Lee & Quam, 2013). Many LGBTQ persons residing in rural communities create private or secretive lives that focus on relationships within closed support networks that may include biological and legal kin, families of choice, and friends and neighbors (Lee & Quam, 2013). Overwhelmingly, research suggests that the emphasis on privacy is a personal preference and a strategy for surviving within a hostile climate (Lee & Quam; Oswald & Culton, 2003). LGBTQ elders living in rural areas may become more isolated from their families of origin than others. Often, elderly lesbians and gay men may be single, childless, and estranged from family members, which can result in isolation (and susceptibility to mistreatment, mentioned earlier) (Barker & Krehely, 2012).

Geographic location is a significant variable that, due to social, cultural, and economic differences between rural and urban settings, influences how LGBTQ persons experience and express sexual and gender identity worldview (Lee & Quam, 2013) and disability identity (Gay and Lesbian Medical Association [GLMA], 2010). Too often, rural environments allow for only limited information about sexual minorities and typically include aspects of shame, negativity, and pathology (Datti, 2012). Moreover, regardless of the age of the individual, Datti suggested that heterosexist worldviews can be internalized and can affect self-worth, self-perception, and healthy functioning.

Service Delivery Implications for the Vocational Rehabilitation Counselor

Although each human service agency has its own mission, procedures, and policies broadly defined, the responsibilities of human service agencies encompass efforts that are described as helping, preventing, ensuring, empowering, and linking people to resources to improve quality of life. Rehabilitation counselors and other human service providers working with populations with disabilities in rural communities need to consider ways to provide comprehensive and integrated services with multiagency responses. For example, research suggests that, for persons with disabilities, progress in vocational and employments areas is limited until the basic needs of housing, food, and safety are addressed. In addition, service providers need to be trained in understanding how rurality affects the rehabilitation needs of women, older adults, and LGBTQ persons. When individuals seek services, the expectation is that service providers will meet their needs, and, moreover, they trust that the service provider has the requisite knowledge, skills, and abilities to meet their needs (Hartman & Weierbach, 2013).

Rehabilitation counselors first need to conduct a self-evaluation of their values, attitudes, and beliefs about providing services to rural women, older adults, and LGBTQ persons with disabilities. Counselors who are aware of and comfortable with their own identities and *positionalities* are better suited to work with clients of different groups (Sue & Sue, 2013). They should be aware of how unconscious bias may affect their vocational planning and placement for working with those populations. Similarly, rehabilitation counselors should understand the adverse impact of negative societal messages that are often presented and promoted about specific groups. In turn, these messages may influence how an individual responds to services, as well as the perceptions they formulate about their own self-image and abilities. Too often as a result of being marginalized, negative messages and images create further obstacles to empowerment and lessen opportunities for rural women, older adults, and LGBTQ persons (with and without disabilities). For some, there may be further subjugation to a status of invisibility.

Second is a need for an analysis of the current reality of knowledge, service delivery approach, and training needs of rural rehabilitation counselors for working with gender, age, and sexuality-/gender-specific populations. It may be presumptuous to assume that counselors who have been taught about unconditional positive regard, postmodernism, person-environment fit, or another counseling approach are able to apply the concept with women, older adults, and sexual minorities living in rural areas. In fact, education and mandatory diversity training for counselors should be required. Given that a range of years may have passed since some counselors have completed their education, training can provide knowledge that may have not been part of their formal training. Currently, counseling organizations and counselor education curricula include LGBTQ sexuality within the definition of diversity, which may help to reduce resistance from un-and under-informed counselors.

Third, counselors are mandated to practice under the guidelines of a code of professional ethics (e.g., American Counseling Association, American Psychological Association, Commission on Rehabilitation Counselor Certification). Ethical codes of conduct require counselors to provide services that are unbiased, respectful, and nondiscriminatory. Counselors are to engage in behaviors that are affirming of clients. Also, cultural competence in working with people of minority backgrounds is now prescribed by counseling and other human services professions.

Counselors are professionals who are credentialed to provide an array of services to various populations and settings. Thus, counselors can contribute to benefit women, older adults, and LGBTQ persons living in rural areas in several ways: (1) share professional expertise as a member of an advisory committee or task force focused on improving services, (2) engage in research on education, employment, poverty, and disability disparities that affect services, (3) organize and promote advocacy for self-improvement, (4) gain an understanding regarding support systems and begin to understanding the needs for gender-age-and-LGBTQ appropriate services, and (5) identify and help develop LGBTQ resources and services. Moreover, counselors need to be aware of age-sensitive issues of rural LGBTQ adolescents who may be at greater risk of experiencing anti-LGBTQ biases due to their lack of maturity and dependence on school and family (Datti, 2012; Yarbrough, 2003) as well as how these experiences affected adult populations. Because women, the elderly, and LGBTQ persons with disabilities in rural areas each have specific challenges, the remainder of this section will identify service needs specific to each population. It is beyond the scope of this chapter to be all-inclusive of service needs of various groups; thus, the focus is to present specific dimensions of service needs. In addition, the reader is reminded to conceptualize the relevance of the Internet in rural areas. Access to the Internet offers opportunities to converse with doctors, specialists and other medical practitioners, and counselors and human service providers from remote locations. However, for many persons in RFT communities, access to the Internet is still a barrier to connect to services.

Service Needs of Women

The magnitude of challenges among women with disabilities in RFT communities is enormous. Rehabilitation counselors and other human service providers must take into account unique characteristics that may influence service needs of women in general and, more specifically, women in RFT communities. First, women are more frequently affected by chronic conditions and disability than men, and both severe and moderate disability is more common among women than men across age groups. Second, women with disabilities have a higher incidence of certain types of disabilities and have difficulty in accessing healthcare services, social services, or childcare services. Third, women with disabilities are more likely to be poor and unemployed and have limited social support. Fourth, disability affects women's lives in various ways because women are often caregivers for children, spouses, or other family members. Finally, elderly women and women living poverty with disabilities are more vulnerable in general and thus require more targeted policies and interventions (DesMeules, Turner, & Cho, 2004).

In working with women with disabilities in RFT communities, the following recommendations are provided to rehabilitation counselors and other human service providers. First, consider working collaboratively with other human service agencies to provide transportation and coordinate the scheduling of appointments. Availability and access to transportation for poor and elderly women in rural areas are major barriers to accessing services. Resources that can be utilized by partnering agencies' resources may enhance knowledge about persons with disabilities among various professionals and increase agencies as referral source. Second, include strategies to improve health literacy, awareness of the signs of mental illness, advocacy, and financial literacy of rural women as part of counseling and guidance. Third, develop targeted approaches of outreach and case-finding for women in RFT communities. Fourth, educate physicians and healthcare providers about vocational rehabilitation services. Fifth, develop a working knowledge of the signs of domestic and intimate partner violence and neglect and mistreatment because counselors are often one of the first service providers to either suspect or recognize these signs. Women with disabilities who are living in rural areas can face considerable hardships, such as the cyclic effects of poverty, lack of access to shelters and services to address violence, and poor systemic responses to domestic violence, abuse, and assault. All over the world, for women living with disabilities and who are living in rural areas, violence is a growing concern.

Rehabilitation counselors can offer women with disabilities in rural areas a means to strengthen their economic potential through employment, education, or training. Parent (2008) suggests using the approach of "thinking outside the box" in order to assist women with disabilities to gain competitive employment. Options include supported and customized employment (e.g., created jobs, carved jobs, self-employment). In addition, Parent (2008) urges rehabilitation counselors to be role models for women with disabilities as a means of facilitating their goals. Implicit to role modeling is for the counselor to avoid gender stereotyping of what women and men can and cannot. Similar caution must be taken to avoid stereotyping of women due to their geographic location.

Service Needs of Older Adults

There has been little attention given to needs of elderly people living in RFT communities and their needs within vocational rehabilitation (Kampfe, Harley, Wadsworth, & Smith, 2007; Kettaneh, Kinyanjui, Slevin, Slevin, & Harley, 2015), as has been the attention given at the national level by program and policy makers (Krout & Hash, 2015). In a content analysis of select rehabilitation counseling journals, Kettaneh et al. found only 24 articles on aging between 2000 and 2012. This finding is especially disturbing given that older adults make up a greater percentage of rural populations and, compared with their urban counterparts, are more disadvantaged on quality of life indicators (i.e., health, housing, economic resources). In the case of rural elderly people, residential context matters (Krout & Hash). Moreover, Glasgow and Berry (2013) suggest that an understanding of rural aging contributes to the knowledge of impacts of aging in general.

Changes in the economy of rural areas (e.g., decline of extraction industries, manufacturing jobs, and small farms) have reduced employment options and spurred the exodus of a younger workforce. Emphasis has shifted from a sustainable rural economy to one bolstered by government and voluntary and nonprofit subsidies. Further, rural older adults have little political voice due to their race and ethnicity and low socioeconomic backgrounds (Bull Howard, & Bane, 1991). Because many rural older adults will increasingly need to access healthcare, transportation and access to these services are especially critical despite the fact that isolation in RTF areas is magnified by distance to services, especially hospitals, challenging terrain, and quality of roads (Bull, Krout Rathbone-McCuan, Shreffler, 2008). Bull et al. stress that rural areas continue to experience a shrinking tax base, decreases in corporate giving, and reductions in social services as well as healthcare providers (e.g., hospitals, doctors, nurses) as well as an under-trained labor pool, which hampers the introduction of helpful technology, such as the use of the Internet, mentioned above. Mental health providers are also in extremely short supply, and isolation may exacerbate mental health problems.

Case Study

Juanita has lived in a rural area all her life. She dropped out of school after the 8th grade due to her family's need for her to work and married at age 17 to escape her family's impoverished situation. By age 18, she had one child with another born 7 years later. Her husband also had an 8th grade education and ran a small dairy farm on mountainous land until his poor health forced him to sell off most of his farm equipment and land. Their oldest son died of cancer before he turned 40, leaving the younger son, who left the area to pursue an education and to find employment, to help with his mother. Juanita's husband died, leaving her alone in the home and experiencing depression and other health problems to the point that she eventually needed a guardianship. The son, also the guardian, checks on her weekly and phones her daily, but her physical and mental health has deteriorated to the point that she has not left her home in over a year. She is also somewhat afraid to leave the home due to a drug dealer who has moved to property adjacent to her and sharing a common easement that now has a gate and several large and barking dogs. Neighbors do what they can to help, and a relative is paid to bring in food and help with medications. Still, because of the isolation of the rural area, there are very few visitors, and home health services are sporadic in both availability and quality. Also, particularly since her husband's death, Juanita is suspicious of anyone who offers help to her. She vows that if she is forced to go in a nursing home, she will die and blame her son forever for putting her there.

The case study above is representative of many of the problems of older adults whose physical and mental health is deteriorating and who are aging in place in a rural area. Clearly, counselors attending to the needs of older adults must marshal needed services (in particular mental health services) that are too often in short supply. The inadequacy of services for rural older adults increases their vulnerabilities to mistreatment (see above). Counselors must confront the growing social and healthcare needs of older adults who are living in rural areas and find creative ways to target and deliver services to them, services that are of the highest quality possible and delivered in a timely way. Useful strategies include cooperative arrangements for transportation and service delivery. Counselors must be attune to cultivating and enhancing the viable services that do exist as well as the creation of new services as they are needed, being careful to understand that some needs are unique to rural elderly people and are not just urban needs transposed upon rural ones.

Service Needs of LGBTQ Persons

As with the older adults discussed earlier, lack of knowledge on the part of counselors about LGBTQ persons residing in rural communities and a lack of familiarity with their communities, cultures, and worldviews contribute to both LGBTQ persons' status as a hidden minority and their invisibility overall (Datti, 2012; Elisaon & Hughes, 2004; Harley et al., 2014; Harley, Hall, & Savage, 2000). Dispenza, Viehl, Sewell, Burke, and Gaudet (2016) assert that "deficient knowledge regarding sexual minorities living with chronic illness and disability (CID) poses significant implications for rehabilitation counselors, especially as they are expected to ethically address issues of cultural diversity and CID" (p. 144). Additionally, few services exist that are specific to the needs of LGBTQ persons as well as very little outreach to this community (Hughes, Harold, & Boyer, 2011). In 2012 the Association for Lesbian, Gay, Bisexual, and Transgender Issues in Counseling (ALGBTIC) approved counseling competencies for lesbian, gay, bisexual, queer, questioning, intersex, and ally individual (LGBQIQIA) (Harper et al., 2013) and for transgender clients in 2009 (American Counseling Association, [ACA], 2010). The Association's competencies are geared toward ensuring that professionally trained counselors to provide a framework for "creating safe, supportive, and caring relationships with LGBQIQA individuals, groups, and communities that foster self-acceptance and personal, social, emotional, and relational development" (Harper et al., p. 2). The competencies are based on a wellness, resilience, and strength-based approach (ACA).

Dispenza et al. (2016) conducted a study in an effort to understand the effective practices that rehabilitation counselors (RC) reported exhibiting when working with sexual minority persons living with chronic illness and/or disabilities (CID). The results yielded construction of a model of affirmative intersectional rehabilitation counseling with affirmative intersectionality as the core category and four supporting categories: professional attributes (values, virtues, self-awareness) , working alliance (empathy and emotion validation, confidentiality, shifting professional role types, and intentional self-disclosure), intersectional sensitivity (collaborative empowerment and nurturing autonomy), and intersectional interventions (appraising intersectional contextual barriers, mobilizing adaptive resources, and social justice actions). Affirmative intersectionality was the mechanism fueling RCs' overt and covert cognitive, affective, and behavioral processes when delivering professional services to LGBTQ persons living with CID. Each of the supporting categories is salient and is equivalent to the next, with each uniformly contributing to the practice of affirmative intersectional rehabilitation counseling with LGBTQ persons (Dispenza et al.). Dispenza et al. concluded that affirmative intersectionality demonstrates malleability and fluidity and did not focus on any particular counseling theory or technique. That is, when RCs are already operating from diverse and empirically intentional counseling frameworks, the affirmative intersectionality approach lends itself to be pan-theoretical. RCs are able to understand a client from behavioral, cognitive, and emotional perspectives, focusing on a client from a holistic approach that allows for integration of multiple rather than a singular or specialized technique.

Among the many counseling approaches conducive to working with LGBTQ persons, Datti (2012) presents a combination of three known to be helpful: person-centered counseling, feminist theory, and cognitive behavioral therapy. Person-centered counseling emphasizes positive regard, honest relationships, and a nonjudgmental attitude. The application of person-centered counseling starts with a welcoming and safe environment. For LGBTQ persons in rural areas, such an environment signifies trustworthiness and objectivity that affirms their identity to an extent that may not have existed before. A feminist perspective can be used to address societal discrimination experienced by LGBTQ persons in rural settings and allow them to deal with a spectrum of internalized negative attitudes toward sexual minorities and gender identities. Cognitive-behavioral techniques can be used to examine LGBTQ persons' problematic thought processes and substitute more adaptive responses (Datti).

As a function of their job, rehabilitation counselors are required to be familiar with community resources. In rural communities, resources are more limited, and LGBTQ-specific services are virtually nonexistent. For available services, the focus should be on advocacy that includes LGBTQ-sensitive programming (Harley, 2016b). In addition, it may be helpful for RCs to develop a resource manual for themselves and their clients (Datti, 2012). With employment as the primary goal of vocational rehabilitation services, RCs should assist LGBTQ clients with issues accompanying coming out or self-disclosure in the workplace and potential ramifications. Often, the first question is should an individual come out to employers and coworkers? If an individual chooses to come out, the RC, if not knowledgeable, concerning working with LGTBQ populations, should refer the client to someone who is qualified to work with him or her. If the RC proceeds in working with an LGBTQ individual, he or she should discuss workplace-related issues such as discrimination concerns, job accommodations, legal implications, confidentiality, and employer and coworkers' potential responses. Potential negative outcomes for LGBTQ persons in the workplace are adverse impacts on mental and physical health, wage and employment disparities, and forced concealment of sexuality orientation (Sears & Mallory, 2015). (See Bolles, 2015 and TUC Guide, 2013 as workplace resources). RCs should work with employers to identify and promote LGBTQ-friendly and safe-spaces and non-offending language. Counselors always need to be mindful of the workplace setting as well as the cultural views of rural settings toward LGBTQ persons.

Summary

Women, older adults, and LGBTQ populations with disabilities are groups that present unique issues and require specific and sensitively appropriate responses and approaches. Often, these groups may share intersecting identities. Counselors have a unique role in the pantheon of service provision in rural areas, such that they can both help these populations using feminist theories and person-centered counseling at the individual level as well as inform communities about their needs. Because of the special issues that may accompany living in rural areas, women, older adults, and LGBTQ persons with disabilities who are living in rural communities may require services from multiple service providers. When services are well coordinated, individuals tend to receive appropriate services and vulnerabilities to abuse and declines in health may be abated. However, if services are undersourced and the workforce providing them is inadequately trained, vulnerabilities are exacerbated to the point that health and well-being may be severely compromised. The informed, well-trained rehabilitation counselor has the potential to significantly improve the lives of women, older adults, and the LGBTQ populations who are living in rural areas.

Resources

Benchmark Institute (Effective Outreach to GLBT Disability Community): http://www.benchmarkinstitute.org/GLBT/disability-and-GLBT-resources.htm

Gay and Lesbian Alliance Against Defamation (GLAAD): http://www.glaad.org

Human Rights Campaign: http://www.hrc.orgg

National Center on Elder Abuse: http://www.ncea.aoa.gov/

National Council of Aging: http://www.ncoa.orgg

National Institute on Aging: http://www.nia.nih.gov

National Resource Center on LGBT Aging. (2013). *Inclusive questions for older adults: A practical guide to collecting data on sexual orientation and gender identity*. New York, NY: Author

Rural Health Information Hub: http://www.ruralhealthinfo.org

Womenshealth.gov: http://www.womenshealth.gov/index.php

Learning Activities

Self-Check Questions

1. What are some distinguishing needs of women in rural communities that differ from their counterparts in urban areas?
2. What type of environmental factors do rural women face?
3. What are the priorities for action for older adult in rural setting to be able to sustain quality of life?
4. How might rural communities help prevent the mistreatment of its older residents?

Experiential Exercises

1. Develop a report on the status of women with disabilities in a rural area within or near your community.
2. Imagine that you have been asked to testify before Congress about the employment needs of older persons with disabilities. Identify key points and research to support your presentation.
3. Imagine that you are a friend Juanita in the case study earlier in the chapter. What would you do to help her? Her son?

Multiple-Choice Questions

1. What is one of the greatest problems facing older adults living in rural areas?
   (a) Isolation
   (b) Poverty
   (c) Decline in manufacturing
   (d) All of the above
   (e) None of the above
2. Because of a paucity of available service, what is the overall mental and physical health of people living in rural areas as compared to people living in urban areas?
   (a) Better
   (b) Worse
   (c) Same
   (d) No difference
3. Which of the following groups in rural areas is referred to as "the poorest of the poor"?
   (a) LGBTQ
   (b) Children
   (c) Women
   (d) Older adults
4. Which of the following groups send more of their adult lives living with a disability?
   (a) White men
   (b) White women
   (c) Latino men
   (d) Black women
5. What is the average distance to the nearest domestic violence resource for women in rural areas as compared to women in urban areas?
   (a) Two time greater
   (b) Three times greater
   (c) Four times greater
   (d) Six times greater
6. Compared to urban elderly, rural elderly have a heavier reliance on which of the following because of a lack of community-based alternatives?
   (a) Day treatment programs
   (b) Senior center
   (c) Nursing homes
   (d) Disability resource center
7. LGBTQ persons in rural areas face which of the following as a person with a disability?
   (a) Double support
   (b) Double coming out
   (c) Increased service opportunities
   (d) Better experiences with civil rights
8. Which of the following is more of an issue for LGBTQ persons in rural areas then their counterparts in urban areas?
   (a) Lack of a visible gay community
   (b) Lack of LGBTQ-specific services
   (c) Social isolation
   (d) All of the above
   (e) None of the above
9. Which of the following is implicit to role modeling for the counselor to avoid in working with women in rural areas?

   - (a) Gender stereotyping of male and female roles
   - (b) Familiarity with community resources for women
   - (c) Referral to qualified service providers
   - (d) Identification of wage and employment disparities

10. Compared to urban areas, which of the following make up a greater percentage of rural populations?
   - (a) Women
   - (b) LGBTQ
   - (c) Children
   - (d) Elderly

Key

1 – D
2 – B
3 – C
4 – D
5 – B
6 – C
7 – B
8 – D
9 – A
10 – D

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12

Offender Populations with Disabilities in Rural Settings

Debra A. Harley and Lisa Dunkley

Overview

Increasingly, rehabilitation counselors and job placement specialists find themselves working with persons with disabilities who also have criminal backgrounds. The presence of a disability may allow ex-offenders to apply and qualify for VR services. As a group, ex-offenders, especially those in rural settings, possess both unique individual and community characteristics that deny them access to traditional avenues of employment (Harley & Feist-Price, 2014). A criminal record limits opportunities for employment. In addition, employers' attitudes and hiring practices influence employment outcomes of ex-offenders. According to the Housing Assistance Council (2011), ex-offenders reentering rural communities are faced with specific housing challenges including a short supply of rental and transitional units, housing that is suppressed by quality and affordability constraints, the composition of rental housing that is typically single-family homes or small multifamily structures, and older or manufactured housing. Although employment is a significant predictor of future success of ex-offenders, addressing the offender's antisocial attitudes, criminogenic beliefs, peer groups, and personality patterns is equally important (Justice Center, The Council of State Governments, 2013).

Prior to the passage of the Americans with Disabilities Act (ADA), inmates with disabilities had very limited rights and essentially no access to accommodations. "The ADA was developed to ensure that people with disabilities have equal opportunity to participate in or benefit from public programs, services, and activities" (Krienert, Henderson, & Vandiver, 2003, p. 14). Moreover, Title II of the ADA prohibits discrimination based upon disability within all state and local governments. The ADA in conjunction with the decision of the Supreme Court in 1998 (i.e., Yeskey v. Pennsylvania) extended equal rights to inmates with disabilities, requiring government entities, including correctional institutions, to make their facilities, program, services, and activities accessible to both inmates and their visitors (Krienert et al.). See Discussion Box 12.1 for specific requirements.

Research has demonstrated differences exist between rural and urban communities, and as a result community can influence criminal behavior, culture, demography, and crime (Pfortmiller, 2011). Reentry into rural communities shows ex-offenders face difficulties as it relates to employment, housing, transportation, substance abuse,

D.A. Harley (✉)
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: dharl00@email.uky.edu

L. Dunkley
University of Kentucky, Lexington, KY, USA

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Discussion Box 12.1

Krienert, Henderson, and Vandiver (2003) described the requirements of the ADA for correctional institutions for inmates with disabilities and their visitors to make their facilities, programs, services, and activities accessible. These requirements include the following: (1) modify their programs if there are policies or procedures on the record that discriminate on the basis of disabilities, (2) modify the architectural design of buildings to accommodate disabilities, and (3) make sure that inmates with visual, speech, or hearing disabilities have appropriate mechanisms for communication. In Yeskey v. Pennsylvania, Yeskey was an inmate with a history of hypertension who was denied access to a motivational boot-camp program, which allowed inmates to be released on parole earlier than those who did not complete the program.

Questions

1. In what way was Yeskey discriminated against?
2. What ethical principles were violated in denying Yeskey access to a boot-camp program?
3. Do you believe ADA rights should have been extended to inmates? Why or why not?

and mental health treatment (Ward, 2016; Lurigio, Ward, & Merlo, 2016). Furthermore, offenders perceived structural barriers as their biggest hurdle to reentry, which include payment of fees and fines, while practitioners saw personal barriers of reentry of inmates as biggest hurdles to successful reentry (e.g., housing, lack of employment opportunities, and transportation).

Learning Objectives

Upon completion of this chapter, the readers should be able to:

1. Identify barriers to employment for ex-offenders.
2. Identify barriers to community reintegration for ex-offenders.
3. Understand the differential effects of disability because of gender-related experiences.
4. Identify ways in which rurality impacts ex-offender community reintegration and employment opportunities.
5. Identify ways in which rehabilitation counselors, job placement specialists, and other human service providers can assist the ex-offender with transition reentry and employment.

Introduction

The United States has the highest incarceration rate of all countries in the world. In 2012, there were almost 7 million adults incarcerated in the United States (Glaze & Herberman, 2013). It is estimated that between 12 and 14 million, ex-offenders are of working age, and about 1 in 33 working-age adults is an ex-prisoner and about 1 in 15 working-age adults is an ex-felon (Bureau of Justice Statistics, 2011). The number of adults convicted of crimes has increased exponentially over the last decade, and it is estimated the number of ex-offenders of working age will likely rise substantially in the coming decades (Western & Pettit, 2010). Upon returning home, support systems and resources are not available for many ex-offenders. Reintegration into the community presents numerous barriers, including but not limited to employment, stigma, financial obstacles, educational limitations, transportation, addiction problems, legal issues, family adjustment concerns, attitudinal barriers, access to housing, and collateral consequences such as being barred from voting or civic participation and public housing or family participation (Ewert & Wildhagen, 2011; Fahey, Roberts, & Engel, 2006; LePage, Washington, Lewis, Johnson, & Garcia-Rea, 2011; Solomon, 2012). Most notably, the lack of and limited use of skills and changing technologies during incarceration may reduce marketable work skills (LePage et al.). Although prisons offer work assignments with the chance to learn basic job skills (e.g., electronic assembly), most of the work opportunities are in low-skilled positions such as food service, janitorial, and furniture assembly (Solomon, Johnson, Travis, & McBride, 2004). In addition, the acceptance of ex-offenders in rural areas may be further hampered by requirements of retribution and personal values within the community (Garland, Wodahl, & Schuhmann, 2013).

Though reentry among rural ex-offenders may not differ significantly from their urban counterpart, challenges upon reintegration in society exist nonetheless. By examining a rural community within a broader context, however, one can then uncover the specific difficulties ex-offenders face upon reentry. For instance, by identifying or defining a community's cultural values, social interactions (i.e., strong community involvement and social connectedness), population demographics (average age, religious values), and economic conditions, rehabilitation counselors, job placement specialists, and other human service providers can implement a proactive approach to enable this population to successfully reintegrate within society (Wodahl, 2006). Too often, however, service providers carry stigmatizing perceptions of ex-offenders, which inhibit a positive working alliance, ultimately affecting successful rehabilitation outcomes (Schneider & McKim, 2003). Therefore, the broader perspective concept can improve the working relationship by understanding the context of change (i.e., the needs, deed, and demographic characteristics) and the change process (i.e., desistance from offending in terms of age and maturity, the development of positive social bonds, and the way ex-offenders construct their personal and social identities) and supporting change through interventions (i.e., risk classification, criminogenic needs, responsivity, community base, treatment modality, and program integrity) (McNeill, Batchelor, Burnett, & Knox, 2005). Several of these principles are discussed later in the chapter. According to McNeill et al., knowledge about these processes are essential for the counselor to understand not only what works in terms of interventions but also of *how* and *why* ex-offenders in rural areas come to change their behavior.

Characteristics of Offender Populations

By the age of 23, one-third of American adults have been arrested (Barnes, Turner, Paternoster, & Bushway, 2012). Criminal records range from onetime arrests where charges are dropped to lengthy, serious, and violent criminal histories (Solomon, 2012). Ex-offenders with intellectual disabilities, mental health disorders, substance abuse, or co-occurring disabilities have a high level of historical contact with the legal system (Harrell & Rand, 2010; Weiss, 2013). Educationally, the offender population has lower levels of educational attainment than the general household population as well as the economically disadvantaged household population (Ewert & Wildhagen, 2011).

Several studies have reported rural and urban differences in drug use, higher DUI arrest rates and fewer treatment programs (Webster, Dickson, Duvall, Clark, 2010). There is limited research on differences in recidivism and behavioral health predictors (substance abuse and mental health) among offenders paroling in urban and rural areas. Urban offenders are more likely to participate in community treatment aftercare following release than offenders in rural communities (Staton-Tindall, Harp, Winston, Webster & Pangburn, 2015). In addition, rural offenders who recidivate were younger, unmarried, and less likely to be employed, have relapsed to drug use, and were more likely to have had acquired a new charge compared to parole violation. Marital status is a significant predictor of recidivism in rural areas and may be attributed to the social bonds, kinship, and relationships that are more common in rural areas. Furthermore, no gender differences were noted in return to custody offenders in rural areas as opposed to differences found for urban offenders. Supporting past research, male offenders were more likely to recidivate and return to prison than female offenders living in urban communities (Staton-Tindall, et al., 2015).

The majority of ex-offenders are racial or ethnic minorities (i.e., African American and Latino), and they constitute the majority of imprisoned offenders in prison or jail and on parole or probation (Glaze, Bonczar, & Zhang, 2010; Guerino, Harrison, & Sabol, 2012; West, Sabol, & Greenman, 2010). Although African Americans are still incarcerated at dramatically higher rates than Whites, there is a notable increase in the incarceration of White women. In the offense categories of violent crimes, property crimes, and drug offenses, White arrest rose for both property and drug offenses (Mauer, 2013). Male and female offenders also differ in the types of offenses for which they are incarcerated. Females have higher rates of incarceration for drug offenses and property crimes, whereas males have higher rates violent crimes, property offenses, and sexual offenses (Ewert & Wildhagen, 2011). Pathways into crime also vary by gender. Females have a stronger correlation between prior victimization and offending, histories of physical or sexual abuse, and intimate partner violence (Covington, 2007).

Byrne and Trew (2008) postulate that women offenders committed crime motivated by restricted resources as opposed to intrinsic rewards. Female offenders commit crimes as a means to provide for their children out of fear of being deemed a bad mother and their children taken into custody. In addition, problems manifested from childhood such as abuse, domestic violence, and substance abuse contributed as a coping factor to life's difficulties and were linked to offending. Having restricted resources and limited choices, unemployment and being single parents acted as motivators to offending. Being female offenders was perceived with disdain owing to conflicts with conventional social values. Compared to males, female offenders are introduced to crime through relationships with family, friends, and significant others (Cobbina, 2009). Women who are romantically involved with men frequently engaged in criminal activities increase their criminal opportunities and maladaptive behaviors (Richardson & Flower, 2014). Upon release from prison, female ex-offenders report more frequent and severe experiences of gender discrimination than male counterparts, especially in relation to drug offenses (van Olphen, Eliason, Freudenberg, & Barnes, 2009).

Ex-offenders identified six factors that influence their ability to reintegrate and abstain from reoffending: (a) substance abuse, (b) employment, (c) family support, (d) types of friends, (e) personal motivation, and (f) age (in relation to maturity) (Davis, Bahr, & Ward, 2012). The majority of offenders identified support from family, friends, and substance abuse treatment services as important for successful reintegration. In addition, both a personal desire to change and a support system helped ex-offenders to reintegrate and desist from drug use and crime. Support had more impact among those who desired to change, and those who received support were more likely to perceive that change is possible (Davis et al.). In a study by Bahr, Harris, Fisher, and Armstrong (2010), the authors found substance abuse courses offered in prison increase successful parole outcomes, and upon release, ex-offenders are more likely to engage in enjoyable activities with family and friends. Employment was also positively correlated with successful parole outcomes. For example, those that worked at least 40 h per week are more likely to complete parole successfully. Additionally, ex-offenders who had more support from family and friends, and had some self-efficacy, were more likely to stay away from drugs and persons who may influence them to revert to previous mischievous behavior. The Bahr et al. study found the results consistent with an integrated life course theory.

Rarely are ex-offenders thought of as vulnerable or marginalized; rather, they are seen as perpetrators against those who are vulnerable (Harley, Cabe, Woolums, & Turner-Whittaker, 2014). “Vulnerability involves several interrelated dimensions: capacities and actions, availability or lack of intimate and instrumental support, and neighborhood and community resources that may facilitate or hinder personal coping and interpersonal relationships” (Mechanic & Tanner, 2007, p. 1222). According to Geiger (2006), ex-offenders occupy one of the most marginalized positions in the United States and that marginalization has become more extreme as a result of "the War on Drugs, the criminalization of poverty, mental illness and addiction, the technological advancement of criminal recordkeeping, and the media promotion and distribution of the image of the pathological criminal through popular culture" (p. 1191). Ex-offenders with disabilities are at risk for multiple vulnerabilities because they are politically, economically, socially, and legally ignored, excluded, and neglected in regard to employment and civil liberties. Research exposes the susceptibility of ex-offenders to workplace discrimination, discrepancy between employers' stated attitudes toward the hiring of ex-offenders and their actual hiring practices (Holtzer, Raphael, & Stoll, 2003, 2004, 2007; Schmitt & Warner, 2011; Varghese, Hardin, Bauer, & Morgan, 2010), limited education (Cronin, 2011), barriers to citizenship rights and legal disenfranchisement (Chung, 2013), and health issues, poverty, social stress, lack of social support, rurality, disability, and various personal limitations (Communities and Local Government, 2008; Geiger, 2006; Mechanic & Tanner, 2007; Pager, 2007; Sokoloff & Burgess-Proctor, 2011). Overwhelmingly, for ex-offenders these vulnerabilities are persistent rather than temporary ones (Harley et al., 2014). We contend that the vulnerability of ex-offenders in rural communities is fueled rather than supported by "social capital" (ways in which networks are linked), "building capital" (to build reciprocity and social solidarity through shared norms and loyalties), and "bonding capital" (to exclude and isolate ex-offenders from community reintegration and social and employment opportunities) (Mechanic & Tanner).

Disability Among Ex-offender Populations

Overwhelmingly, the literature on offenders is concerned with cognitive and intellectual disorders, mental health issues, and substance abuse and is limited with respect to physical, sensory, or other types of disabilities. Otherwise, the literature addresses types of disabilities among offenders with respect to a particular vulnerability status in prison and risk factors (Harley et al., 2014). For example, Krienert et al. (2003) examined data collection practices, the number of offenders with physical disabilities, and services available to those with physical disabilities residing in state correctional facilities. The study revealed that some states did not have these data and did not know where to find programs within their jurisdiction. The diagnosis of attention deficit hyperactivity disorder (ADHD) and conduct disorder is overrepresented among the offender population when compared to the general population (Lindsay et al., 2013). Belcher (2014) stresses that ADHD can be, for some people, a pathway to prison because despite interventions at an early age, some people still develop antisocial and criminal behavior.

The type and degree of disability differs among ex-offenders based on gender because women and men experience disability differently. Compared to males, a larger percentage of female ex-offenders have histories of mental health disorders and co-occurring substance abuse and mental health issues (Center on Addiction and Substance Abuse, 2010; McPhail, Falvo, & Burker, 2012). Specifically, women offenders have a higher prevalence of post-traumatic stress disorder (PTSD) due to exposure to traumatic events such as physical and sexual abuse, borderline personality disorder (BPD), depression, and substance abuse. According to McPhail et al., to meet the needs of female offenders, treatment and rehabilitation programs are necessary at all three levels of rehabilitation: in prison, the transition from prison to the community, and within the community. The type of disability also varies based on race/ethnicity. White offenders self-report higher prevalence rates of mental health problems than their counterparts (James & Glaze, 2006). Compared to Whites, Black and Latino males are twice as likely to be HIV positive, whereas female offenders of color are about six times as likely (Maruschak, 2006).

People with intellectual, cognitive, and developmental disabilities get involved with the criminal justice system as both victims and suspects/offenders. Individuals with intellectual, cognitive, and developmental disabilities become victims of crime because of insufficient adaptive behaviors, constant interactions with "protectors" who exploit them, lack of knowledge on how to protect themselves, and living and working in high-risk environments that increase their vulnerability to victimization (Davis, 2009). As victims or suspects, people with intellectual disabilities may encounter the following problems: (a) they are frequently used by other criminals in law-breaking activities without understanding their involvement in a crime or the consequences; (b) they have a strong need to be accepted and go along to fit in; (c) they unintentionally give misunderstood responses to officers, which increase their vulnerability to arrest and incarceration; and (d) once in the criminal justice system, they are less likely to receive probation or parole because of an inability to understand or adapt to prison rules (Davis).

Research suggests the link between substance abuse and recidivism is substantial. Early studies identified more frequent use of alcohol and sedatives in rural drug abusers than urban ones (Blazer et al., 1985; Gamm, Hutchinson, Ballamy, & Dabney, 2002; Lambert, Gale, & Hartley, 2008; Leukefeld et al., 2002). More recent reports of substance abuse reveal substantial drug abuse problems in rural areas (Dixon & Chartier, 2016). According to Dixon and Chartier (2016) in a review of alcohol use patterns among urban and rural residents, alcohol use disorder (AUD) was lower for urban residents than for rural residents (29.6% and 33.3%, respectively). Rural drinkers were more likely to report a past year AUD. They found rural drinkers were more likely to surpass the recommended daily drinking limit for men (four drinks) and women (three drinks). Despite changes in rates for alcohol use and for driving under the influence (DUI), the rate of DUI arrests has significantly increased for female offenders and has remained higher in rural areas of the country (Webster, Matthew, Harp, Clark & Staton-Tindall, 2009). Moreover, being underage, drug problems, meeting clinical criteria for substance abuse and dependence, and being referred to substance abuse treatment as opposed to education-based intervention and referral noncompliance and multiple DUI offenses have been attributed to rurality (Webster et al., 2009).

Substance Abuse Treatment

In rural communities, seeking treatment and services for substance abuse and mental health may be faced with barriers compounded by low socioeconomic status, cultural disparities, language barriers, and geographical challenges (Benevides-Vaello, Strode, & Sheeran, 2013). Treatment approaches grounded in urban approaches cannot be transferred and used in rural areas without changes conducive to the population (Leukefeld, Godlaski, Clark, Brown, & Hays, 2002). (See Chap. 28 on substance abuse.) The use of telecommunication in health care has shown to be effective in removing some of the barriers attributed to access to treatment and services. The use of video conferencing, telerobotics, picture phones, and interactive video platforms (telehealth) has increased access to specialty services, health information, and health education where services will otherwise be inaccessible to individuals in rural communities at a rate comparable to those in urban areas (Benevides-Vaello et al., 2013; Frueh, Henderson, & Myrick, 2005). Furthermore, telehealth or telemedicine has been advantageous in filling the gap for shortages of care providers that are one of the primary barriers to mental health and substance abuse services in nonmetropolitan areas in addition to transportation difficulties. (See Chap. 4 for discussion on the use of technology.)

In rural areas the rate of substance abuse is close to those in urban communities; however, greater disparities are found in the continuum of services for patients with substance use difficulties (Chan et al., 2015). Referrals to treatment are often by the criminal justice system, and individuals referred with substance abuse disorders often have comorbid psychiatric conditions, social difficulties, and psychical illness. Very few individuals seek and receive adequate treatment, which results in many individuals not benefitting from treatment and specialty health services. Lack of health insurance, underserved minority populations, and low income contributes to the lack of health-care services and is exacerbated in remote rural areas where shortages of professionals and behavioral facilities exist (Chan et al., 2015). Warner and Leukefeld (2001) posit the lack of transportation plays an important role in treatment utilization of rural residents. Rural residents that identify with the lesbian, gay, bisexual, transgender, and questioning (LGBTQ) community face additional barriers such as stigma, negative attitudes that affect their well-being and health-care-seeking behaviors. A comparative study between rural and non-rural transgendered individuals reports overall similarities in substance use behaviors for heavy alcohol use, illicit drug use excluding marijuana, and small differences in binge drinking (10% rural vs. 7% non-rural) for transgendered participants (Horvath, Iantaffi, Swinburne-Romine & Bockting, 2014). High levels of self-reported substance use in probationers in rural communities show a need for treatment services. Individuals may be faced with additional barriers in receiving services, which may give an account for underused treatment services by probationers (Oser, Harp, O'Connell, Martin, & Leukefeld, 2012). According to Oser et al. (2012), prescription opiates and methamphetamines tend to be higher in rural areas, and individuals on probation more likely abuse cocaine and alcohol than non-probationers. Without treatment, offenders that are substance abusers are likely to be repeat offenders, which increase the likelihood of recidivism among probationers. Leukefeld et al. (2002a) posit that incorporating and reinforcing a social skills component in substance abuse treatment where motivational interviewing, using structured stories, and role-playing may be effective in getting substance abusers in rural areas to talk about their problems and get engaged in the treatment process.

With the investment in therapeutic communities (TCs) in prison for substance abuse and alcohol treatment, a reduction in cost of drug-related crimes can be observed at a rate of $4.00–$7.00 (NIDA, 2012; Staton-Tindall et al., 2015). The use of TCs operates under the principle of behavior change and has been shown to have positive results for the reduction of drug use following release, thus minimizing recidivism (Staton-Tindall et al., 2015; De Leon, 2010). Moreover, they postulate behavioral indicators, treatment utilization and other factors affect recidivism among participants released to urban and rural areas, and limited research exists demonstrating the effects of these factors. Findings from research carried out by Staton-Tindall et al. (2015) state that abstinent rate for both rural and urban offenders 1 year post release was similar, but urban offenders were more to engage in lifetime substance use treatment and self-help groups than rural offenders. Rural offenders were more likely to return to prison for new charges and less likely to report a substance abuse treatment history.

Employment Barriers

Barriers to employment are considered to be one of, if not, the primary reasons for high rates of recidivism among ex-offenders regardless of geographical location. According to Visher, Winterfield, and Coggeshall (2005), "one consequence of the tremendous growth in the number of persons under supervision of the criminal justice system, whether incarcerated, on parole, or on probation, is the effect of this criminal history in finding and keeping a job" (p. 295). However, Freeman (2003) argues that because offenders also did less well in the job market before incarceration, it is unclear whether incarceration per se reduces their employment and earning prospects. In this section, we present some of the most common barriers to employment for ex-offenders. These barriers are not necessarily distinct to rural areas but should be considered within that context.

In most rural areas, employment prospects are low. Unlike decades ago when rural residents worked primarily in the area in which they lived, today rural residents commute long distances to work. Within rural communities ex-offenders have to compete with local residents for existing jobs. Applying for jobs in rural communities in which they live, ex-offenders have the disadvantage of everyone knowing each other, which makes it more difficult to avoid knowledge about their criminal history preceding them. As the job market becomes more compressed, the more difficult it becomes for ex-offenders in general and specifically rural ex-offenders to find employment. Often, the presence of a criminal record has a significant adverse effect on a person's job prospects in terms of employer's perception and an ex-offender's self-esteem (Holtzer et al., 2003). In fact, because of the likelihood of rejection in the job search process, ex-offenders need support in building self-esteem and staying the course. Just as with the ex-offender, rehabilitation counselors and job placement specialist will need to practice the art of patience and realize the job search process may be more elongated than short. In addition to providing motivation, rehabilitation counselors must be actively engaged in advocacy practices as it pertains to ex-offenders in rural communities (Ethridge, Dunlap, Boston, & Staten, 2014).

Another major barrier to employment of ex-offenders is the type of offense. Depending on the type of criminal offense, especially a felony, and regardless of how long ago the offense occurred, the person is automatically disqualified from certain employment opportunities (e.g., nursing home or medical attendant, childcare, any vulnerable population, barbering, plumbing, bartending, ambulance driving) because of legal restrictions on hiring ex-offenders (Holzer, Raphel, and Stoll, 2004). In addition to the limitations imposed on the ex-offender as a result of his or her offense, more than 38,000 statues impose "collateral consequences" (American Bar Association, 2011), thereby creating additional barriers, of which more than 80% operate as a denial of employment opportunities (Blumstein & Nakamura, 2009; Solomon, 2012). Thus, public policies aimed at being "tough on crime" (Pogorzelski, Wolff, Pan, & Blitz et al., 2005) have become a double-edge sword for ex-offenders. On the one hand, policies have eliminated public benefits and on the other hand have eliminated access to many of the better paying jobs in which ex-offenders could earn a better standard of living. Within a rural context, these policies magnify the challenges of the job search for ex-offenders. Moreover, Freeman (2003) suggests ex-offenders' values or preferences that lead some persons to choose crime over legitimate activity can be critical in community and employment reentry.

The job application process provides additional challenges for ex-offenders when seeking employment, specifically, difficulty in responding to questions on job applications or interviews that ask about one's criminal record, frequently posing additional barriers toward successful employment outcomes. Overwhelmingly, the literature emphasizes the ex-offenders should not lie about his or her criminal record, rather, he or she should focus on presenting ways that demonstrate what they have gained from the experience and how they have turned their life around. For example, in discussing criminal background during the interview process of an application, the Workforce Professionals Training Institute (2006) recommends the following:

1. Express remorse. Employers like to see that a person knows what happened was wrong, since it shows personal reflection and growth and a desire for change.
2. State *that* you have changed. It can be as simple as saying "I am a different person today."
3. Explain *how* you have changed by listing the positive steps you have made in your life. This can cover a wide variety of areas – education, military service, work history, volunteer activities, and/or skills obtained in or outside of prison (p. 1).

According to the Workforce Professionals Training Institute, employers ask about criminal history not because they are particularly concerned about the actual event but out of a belief that past behavior predicts future behavior. As a job seeker, the ex-offender needs to demonstrate that he or she has changed his or her ways and will be a reliable, productive, and trustworthy worker. In the end, employers need to feel confident about whatever happened in the past will not be repeated. The basic premise of the recommendations by the Workforce Professionals Training Institute (2006) is that it is vital for the ex-offender to “shift the conversation from the negative (i.e., what happened in the past) to the positive (i.e., what I can do for you today)” (p. 1).

As part of the job search, it is important for ex-offenders to know their rights. Lack of knowledge about their rights and the do’s and don’ts of the job search process is another barrier for ex-offenders. For example, in some cases ex-offenders do not have to reveal their history (e.g., when an arrest does not result in a conviction, a minor drug offense occurred and a certain number of years have passed since the conviction, or when one has erased the offense by obtaining a certificate of rehabilitation or similar document) to potential employers. It is, however, important to note that ex-offenders must avoid lying on job applications, which is a criminal offense (Harley et al., 2014; Mulqueen, 2013; Solomon, 2012). (See Table 12.1 for sources of ex-offender rights.) The Equal Employment Opportunity Commission (EEOC, 2012) recommends the following guidelines for employers to consider in reference to the applications of an ex-offender: (a) the nature of the offense, (b) the length of time since the last offense, and (c) the relationship of the offense to the job duties, rather than simply screening out anyone with a criminal record.

The counterpart to ex-offenders’ right in employment is “negligent hiring laws” (NHLs) that pertain to employers. NHLs are state laws specifying accountability among employers for criminal acts of their employee, particularly when reasonable caution is not taken during the hiring process (Mukamal, 2001). Because of the potential for liability, employers almost always err on the side of caution and not hire ex-offenders. A further point of contention for employers is the perception that the sources of protection of ex-offenders’ rights (see Table 12.1) create liability for them. The best advice to employers is to make sure they do due diligence in the hiring process of ex-offenders and simultaneously not violate their civil rights.

Furthermore, the impact of having a criminal record is exacerbated for racial or ethnic minorities. The criminal record penalty is substantially greater for African Americans and Latinos than for White applicants in the job market (Harwin, 2013; Pager, Western, & Bonikowski, 2009; Solomon, 2012). Ex-offenders of color experience double stigmatization because of race and offender status and triple stigma because of a disability, especially a mental health disorder or substance abuse (Pager, 2007).

Table 12.1 Sources of ex-offender rights

Ban the Box
Equal Employment Opportunity Commission (EEOC)
Fair Credit Report Act
Title VII of the Civil Rights of 1964
Certificate of Relief from Disabilities (misdemeanors and/or only one felony, applied for immediately after conviction)
Certificate of Good Conduct (more than one felony, applied for 3–5 years after completing a sentence)
Proof of Rehabilitation (allows an ex-offender to have occupational disqualifications lifted. The method to determine rehabilitation for employment purposes is defined by the state)
State laws on: (1) Waiver and appeal of disqualifying offenses, (2) restoration of eligibility for employment and occupational licensing, (3) expungement and sealing of criminal records, and (4) securing identification documents
The Second Chance Act of 2007, Reauthorization 2013

Adapted from EEOC (2012), Mulqueen (2013), Rodriguez, Farid, and Porter (2011), and Solomon (2012)

There is minority overrepresentation of ethnic minorities incarcerated in the juvenile and criminal justice system compared to their White counterparts that are being assessed for a psychiatric facility. Minority youths are more likely to face trial as adults and sent to jail than White youth who commit similar crimes (Rodney & Tachia, 2004). In an exploratory study of a rural juvenile court in Ohio, Mallett (2010) found that minority youth successfully completed probation more often than any other youth populations. Driving under the influence is more frequent in White, biracial, and Native American males and arrest rates for DUI more prevalent in rural communities (Dickson, Wasarhaley, & Webster, 2013). According to Willging et al. (2013), the prevalence of mental illness and substance dependence of rural Hispanic and Native American prisoners was high and similar to studies of minority women incarcerated. The lack of supports increasing the risk of homelessness was found as a result of insufficient government-subsidized housing and economic hardships. Substance abuse and mental health treatment services are often unmet for female ex-offenders living in rural areas owing to insufficient mental health care and available services in rural areas (Willging et al., 2013).

Many ex-offenders have low educational attainment and experience difficulties in addition to those associated with having a criminal record which impacts employment and employability in addition to having a criminal history. Characteristically, ex-offenders have less education, deficit in work experience and cognitive ability, higher instances of substance abuse, and physical and mental health disorders when compared to the rest of the population (Pettinato, 2014). Vaselak (2015) explains how educational attainment of offenders may be influential in the level of crime committed. Individuals with higher educational attainment risk more if they choose to engage in criminal activities and are less likely to engage in crime because it may not be beneficial to them. However, crimes are not exclusive to individuals with low-level educational attainment; some criminal activities are deemed low skilled, e.g., drug dealing and assault where individuals of a lower educational attainment may engage in. Increased educational attainment may lead to higher-level crimes like white-collar crimes (e.g., fraud and forgery) notoriously associated with those of high social status and yield higher returns (Vaselak, 2015).

Sabates (2008) posits higher education is positively related to reductions in criminal behavior and is also associated with crimes that require specialized skills and is associated with older adults. Moreover, crimes committed that require minimal skills tend to be committed by young individuals with little education. Burglary, vandalism, theft, and drug-related crimes are associated with low-level skills set and examples of such crimes. Socially disadvantaged adolescents may choose a high-risk life of crime owing to the perception of earning a higher reward as opposed to those associated with low scholastic achievements (Sabates, 2008). Immigrants are often characterized as having low socioeconomic status and criminogenic tendencies, which have been depicted by the media (Vaughn, Salas-Wright, DeLisi, & Maynard, 2014). They put forward immigrants to the United States are less likely to engage in nonviolent antisocial and violent behavior than native-born Americans.

Stigma of being an offender is an additional barrier for both the ex-offender and the employer. In regard to employer stigma, the employer is able to move the ex-offender to a status of "not quite human," as described by Goffman (1963). Goffman defined stigma as "an attribute that is deeply discrediting" (p. 3), which allows for the dehumanization of people, thus enabling employers (people) to "exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life changes" (p. 5). LeBel (2012) examined the perceptions of ex-offenders concerning stigma and discrimination they face in society because of their membership in disadvantaged groups and of these perceptions that are related to self-esteem. Ex-offenders identified their ex-offender status as the primary reason for discrimination. The majority of men and women reported being an ex-offender (65.3%) as the primary reason for discrimination, followed by race/ethnicity (48.0%), past drug/alcohol use (47.5), and lack of money or being poor (35.3%). A substantial minority of ex-offenders also reported experiencing discrimination because of gender (15.5%), religious beliefs (11.5%), HIV-positive status (9.5%), and a diagnosed mental disorder (8.5%; LeBel, 2012).

In a study of offenders' expectations of community reentry by Benson, Alarid, Burton, and Cullen (2011), the results were mixed based on race/ethnicity. Benson et al. found White offenders did not feel as though they will be stigmatized as a result of their convictions, and most expect to be reintegrated upon reentry within their community, whereas Latino and African American offenders were less likely to expect successful reintegration. However, the participants were all males, majority Latino and African American, with an average age of 19.5 years and were court ordered to boot camp as an alternative to prison. By merely being in boot camp, White offenders could have the perception that they were not in prison/incarcerated. Conversely, Latino and

African American offenders tend to feel alienated from American society. The results are supported by “both defiance theory and reintegrative shaming theory which predict members of minority groups are at greater risk of experiencing negative stigmatizing treatment than those who are Caucasian” (Benson et al., p. 390).

Finally, recidivism is the ultimate barrier to employment. Although research supports both the success (e.g., Graffam, Shinkfield, & Lavelle, 2014; Pew Center on the States, 2011) and failure (e.g., Moses, 2012; Visher et al., 2005) of ex-offender programs in reducing recidivism, the majority of the literature provides support for the effectiveness of such programing. Tripodi, Kim, and Bender (2010) found that although obtaining employment is not associated with a significant decrease likelihood of reincarceration, it is associated with significantly greater time to reincarceration. For those parolees who obtain employment spend more time crime-free in the community before returning to prison. In a study of 6561 offenders released from the Indiana Department of Corrections (IDOC) in the community shows education and employment were the primary predictors of post-release recidivism. Ex-offenders were more likely to return to custody if they were unemployed and did not complete high school (Nally, Lockwood, Ho, & Knutson, 2012). Research has shown that family ties have strong implication for post-release employment and recidivism as it reinforces identity and recognition (Berg & Hubner, 2011).

Employers’ Attitudes and Hiring Practices

Employers’ attitudes toward ex-offenders can impact successful reentry and reintegration practices (Swensen, Rakis, Synder, & Loss, 2014). Swensen et al. suggest that a lack of collaborative community supports can increase recidivism rates and increase costs to an overburden criminal justice system. One major barrier to hiring ex-offenders is employers often rely on criminal records databases, which can reduce employment outcomes (Paul-Emile, 2014). Finlay (2009) predicts that job prospects for ex-offenders will worsen overtime as employers continue to gain easier and cheaper access to criminal records. Digital profiling of ex-offenders often leads employers to disregard or exclude them from consideration of employment. Furthermore, if an individual has been arrested and not convicted, he or she technically has a criminal record that shows up on a background check (Solomon, 2012).

Holzer, Raphael, and Stoll (2004) found more than 60% of employers refuse to hire ex-offenders. Holzer et al. (2007) explain employers might be unwilling to hire those with criminal records for a host of reasons including risk of legal liability if an ex-offender harms a customer or coworker, the risk of financial liability if the ex-offender engages in theft, fears of personal violence, and negative signals that a period of incarceration have affected their general skills and trustworthiness. In an evaluation of the attitudes of human resource managers toward the hiring of nonviolent ex-offenders who have obtained higher education, McBride-Owens (2013) found ex-offenders’ time since last offense and type of crime committed and its relation to the job duties being advertised as the most important factors when hiring ex-offenders. Varghese, Hardin, Bauer, and Morgan (2010) found that ex-offenders with drug offenses and low qualifications were less likely to be considered for employment. For ex-offenders with misdemeanor charges, qualifications increase employability, but qualifications have no influence for applicants with a felony.

Pettinato (2014) exclaimed that having a criminal record reduces the chances of an ex-offender being hired by approximately 50%. The chances are even slimmer for those offenders that have committed a violent crime. Many employers refuse to hire individuals with criminal record, which will be made apparent when a criminal background check is conducted. However, several states have prohibited ex-offenders from all public employment and/or have restricted them from certain types of occupation. Obtaining employment after incarceration is encountered with the stigma of having a criminal record and the lack of work skills and educational qualifications, which are vital assets for prospective employers in the hiring process. Employers may be unwilling to hire ex-offenders with a criminal record even when they exceed qualifications for the stated position (Berg & Huebner, 2011). There is no evidence indicating an ex-offender's criminal record is indicative of poor job performance. The inability of ex-offenders to obtain employment is more impactful on Black and Hispanic men who are the majority of prison populations. Furthermore, having a criminal record is more likely to hinder African American males than Whites from obtaining jobs (Pettinato, 2014). The criminal background check may be more harmful for Blacks than Whites as statistics show employers "discriminate against black men on the basis of perceived criminality" (Stoll, 2009).

Self-efficacy, self-appraisal, planning, and goal setting are important components of career development of any individual. With unique concerns facing ex-offenders contributing to their high unemployment rate, this process may be difficult. When a career development workshop was carried out between ex-offenders and non-offenders, result indicated no significant differences in self-efficacy, and both parties experienced growth after the workshop (Westerling III, Koch, Mitchell, & Clark, 2015). Ex-offenders are disadvantaged in the labor market due to not accumulating work experience while incarcerated or loss of skills obtained prior to incarceration (Stoll, 2009).

Community Reintegration into Rural Settings

Ex-offenders reintegrating into rural communities face many of the same problems (e.g., transportation, fewer employment opportunities, housing, and cost burden) and civil disabilities as other rural residents; however, ex-offenders are not only impacted more adversely and severely but differently. In addition, the challenges that rural ex-offenders face upon community reentry differ from their urban counterparts. According to Wodahl (2006), "rural communities differ from urban communities in many important ways," and "the unique features of rural communities make it likely that urban-based policies will be ineffective in rural settings" (p. 33). Also, because rural communities are not homogenous, the reader is cautioned to understand the content of this chapter within this context, and not to make broad generalizations. Many of the unique cultural qualities of rural communities can be challenges to ex-offenders' community reentry. For example, rural residents' distrust of outsiders, being less supportive of public programs and resistance to government involvement in their lives, and reliance on solving their own problems create barriers for ex-offenders. And, when support services are available in rural communities, these cultural barriers make it likely that they will be underutilized (Wodahl, 2006). Zajac, Hutchison, and Meyer (2014) examined the challenges and issues related to prisoner reentry to rural Pennsylvania and found that employment, housing, and transportation emerged as key challenges facing ex-offenders returning to rural areas. In addition, stigma of being an "ex-con" also contributes to difficulties in the areas of employment and housing. Social services for ex-offenders are unevenly distributed between rural counties. Ironically, social services may be more readily available in rural counties as opposed to urban areas, but ex-offenders must compete with non-offenders for community social services that are available. (See Research Box 12.1.)

Research Box 12.1

See Zajac et al. (2014).

*Objective***:** This research examined the challenges and issues related to prisoner reentry to rural Pennsylvania including release trends and projections. The four primary research goals were to: (1) estimate the number and characteristics of state prison and county jail prisoners likely to be released into rural Pennsylvania communities over the next 5 years, (2) identify and document reentry programs and services available to released state and local prisoners in rural Pennsylvania, (3) conduct a gap analysis of reentry services available in rural Pennsylvania for successful reentry, and (4) provide public policy considerations.

*Method***:** The study used existing data from the Pennsylvania Board of Probation and Parole and from the study of county jails sponsored by the Center for Rural Pennsylvania and also collected original data through interviews and surveys of key corrections officials.

*Results***:** Releases of county jail inmates to rural counties are projected to hold constant over the next 5 years; however, releases of state inmates are projected to increase slightly over the same time period. The most notable demographic trends among released inmates are an increase in the number of older inmates being released and a slight increase in the number of female inmates being released. Significant reentry needs for returning rural inmates include assistance with employment, housing, and transportation. Social services and programs in rural counties are unevenly distributed between rural counties. Most notably, there are very few reentry programs for sex offenders in rural counties and almost no programs that specifically address the most important rehabilitative needs of ex-offenders, including program that addresses ex-offenders' thinking, decision-making and problem-solving skills, and their peer networks, all of which are strongly linked to recidivism reduction.

*Conclusion***:** Rural reentry will continue to be an important issue in Pennsylvania, as projections indicated a slight increase over time in the number of inmates returning to rural areas, especially inmates released from state prisons.

Questions

1. What are the major challenges facing ex-offenders upon reentry in rural communities?
2. What rehabilitative issues are not being addressed for ex-offenders' reentry into rural communities?
3. What type of offenders has the least access to programs in rural settings?

Many of the services people in transition rely upon, e.g., food stamps, public housing, and Temporary Assistance for Needy Families (TANF), are not typically available to ex-offenders. Pogorzelski et al. (2005) referred to denial of these services as "invisible punishments" for ex-offenders who overwhelmingly entered the criminal justice system from economically disadvantaged communities and, more likely, to return to the same community or a similar one after release. These invisible punishments may have more negative consequences for women ex-offenders' transition back into rural communities for several reasons: (a) women are more likely to meet criteria for substance dependence and abuse (Mumola & Karberg, 2006), (b) women are more likely to have a mental health disorder (Steadman, Osher, Robbins, Case, & Samuels, 2009), (c) women are more likely to have physical disabilities (Maruschak, 2009), (d) women are more likely to be economically disadvantaged (Steffensmeier & Haynie, 2000), and (e) women are more likely to be HIV positive (Maruschak).

Women are more likely to be stigmatized for breaking the law owing to societal expectations of the behavior of a female and femininity. They are faced with many life adversities that involve resource deficiencies, difficult home life, more social problems, poverty, mental illness, substance abuse, and physical and sexual abuse (Estrada and Nilsson, 2012). In addition to gender neutral adversities experienced upon reentry, female ex-offenders face a number of challenges such as victimization, abuse, parental and relationship issues, and mental health issues that require gender-specific attention (Holtfreter & Wattanaporn, 2013). Zust (2009) explains women offenders who are victims of intimate partner violence and at high risk for depression, posttraumatic stress disorder (PTSD), suicide, and other mental illnesses. The need for gender-sensitive interventions to reduce depression in women serves as a means to reduce recidivism and proposes the use of cognitive therapy to raise awareness and empowerment for women.

Reentry into community settings and the employment sector requires ex-offenders to address personal and psychosocial adjustment issues inherent in the transition back into societal living (U.S. Department of Justice, 2014). The inability of ex-offenders to adjust to reentry may contribute to higher recidivism rates. The rehabilitation counselor should help the ex-offender to be prepared to deal with the following realities of reentry into communities:

1. A person with a criminal record is going to face greater challenges in getting employment, which may be exacerbated by rurality. However, "challenging is not the same as impossible" (Rosen, 2003, p. 1).
2. Take the long-term view. "As frustrating as it is, the basic rule still applies – a person must rebuild his or her resume over time. And as time goes by, the criminal offense becomes less of a factor in a person's life" (Rosen, 2003, p. 1).
3. "To deal with the stigma associated with being incarcerated and having a criminal record which may negatively impact all aspects of community reintegration including vocational, financial, social and educational" (Harley, 2014, p. 3).

Post-incarceration and Transition to Rural Communities

Ex-offenders often lack sufficient human and social capital to help them navigate the challenges of life outside of prison (Morani, Wikoff, Linhorst, & Bratton, 2011; Wilson & Davis, 2006). In addition, almost half of ex-offenders have multiple medical problems, chronic conditions, or disabilities "that it is unrealistic to expect them to reenter society as 'normal' productive citizens without much greater assistance than the U.S. has been willing to provide" (Freeman, 2003, p. 11). The Affordable Care Act (ACA) as of 2016 was still in place by virtue of the US Supreme Court's decision to uphold most provisions of the act. The ACA has implications for the criminal justice system including "the potential to reduce crime, recidivism, and criminal justice costs, while simultaneously improving the health and safety of communities" (Bainbridge, 2012, p. 3). Bainbridge states, however, that the US Surgeon General has identified the criminal justice population as a cost containment opportunity for health-care systems. Thus, the true impact of ACA remains to be seen for the offender population.

Preparation before release for reentry into communities and access to services, resources, and opportunities are recognized as key in helping ex-offenders obtain employment, reduce recidivism, and establish positive participation in society. Establishing multiagency initiatives, which often begin with in-prison services, is designed to prepare offenders for transition out of prison (Manpower Demonstration Research Corporation [MDRC], 2013). Transition planning while the offender is still incarcerated is critical to success once released for several reasons. First, exposure to crime as a way of life while incarcerated can serve as a stumbling block to rehabilitation through work (Holzer et al., 2003). While incarcerated, offenders may have ongoing exposure to and participation in violence. There exists an opportunity to change these types of behaviors and learn new ones that are appropriate for the workplace. Once released, the rehabilitation counselors can use various counseling techniques to work with the ex-offender on appropriate behavior, as well as recognizing consequences of inappropriate behavior. Second, once released and engaged in job search, the ex-offender typically will find the process to be lengthy and time-consuming, and the outcome may be a job with low pay and no benefits. In turn, the ex-offender may be tempted to return to criminal activity as a means of support. Again, there is an opportunity to work with the offender before release on various coping strategies, which can be continued post-incarceration. Third, because while incarcerated the primary focus is on exhibiting non-confrontational behavior and serving time as uneventfully as possible, limited attention is given to long-term goals (National Institute of Corrections, 2006). Having offenders to develop a transition plan encourages them to think about life after release. This transition plan can be used in the vocational rehabilitation process to develop an Individualized Plan of Employment (IPE). Finally, according to

Lichtenberger and Weygandt (2011), many offenders fear the lack of structure associated with being released and completing parole, which could become a barrier to community reentry. According to Morani et al., “structural factors have the capacity to facilitate or to hinder ex-offenders’ successful reintegration into the community, thereby impacting their chances of reoffending” (p. 348). The following sections discuss the series of steps that the ex-offender should do upon release.

Getting Connected to Services Ex-offenders face formidable challenges, and upon reentry to the community, primary identified services include employment and vocational, housing, clothing, and transportation (Morani, Wikoff, Linhorst, & Bratton, 2011). Moreover, the rate of recidivism is lower when services needed by ex-offenders are met within 90 days upon release into the community. Transition planning is essential prior to release to identify necessary services and treatment plans. Some offenders being released from prison may be faced with social and personal challenges such as depression, substance abuse, and disorganization from a state of order in prison to disorder in the community setting and require services to aid with the transition and health-related issues. Gender-specific services to combat challenges faced by men and women who are ex-offenders are important in their successful reintegration (Morani et al., 2011). Ex-offenders living in rural communities may have less access to health services. Cason (2009) posits people living in rural communities have less access to care and other specialty services, and the use of telerehabilitation can be used to ameliorate disparities and improve health services and deliver interventions.

Upon release ex-offenders should get connected to community services specialized in helping with primary needs of reintegration such as employment, housing, and treatment. Many reentry services are grant-funded programs to support offenders and provide an array of services (James, 2015). Family plays a key role in the reentry process, therefore seeking support from family in addition to providing families with the education, counseling, and material assistance in helping their loved ones in the reentry process (Gaynes, 2005).

Have an Assessment Once the offender is released from incarceration, an initial step should be to have a full assessment including vocational, psychological, educational, and financial. Concurrently or simultaneously, the ex-offender should do a self-assessment. The self-assessment will assist the ex-offender in making an honest inventory of his or her strength/skills and abilities and challenges, as well as identify related stressors or triggers. In tandem, the full assessment and self-assessment can help to increase the ex-offender’s self-awareness and may help him or her to avoid employment and personal situations for which he or she is not well suited. For example, information from both assessments may help the individual to discover that he or she does not work well under pressure or may find it difficult to work outside (University of Akron Career Center, 2009).

Volunteer Work Often, the initial step to improve quality of life for many ex-offenders is getting their foot-in-the-door for employment and community reentry. While there is great pressure to obtain employment upon release, the rehabilitation counselor and job placement specialist may consider working with the ex-offender to establish volunteer work and/or job shadowing experiences. Granted, neither of these will provide the offender with income, it can however provide them with an opportunity for employment. According to Rosen (2003), “the best way to get a great job in the future is to get any job you can right now, and perform well” (p. 2). According to Morrow-Howell, Hong, and Tang (2009), the benefits to volunteering have been reported to make a difference in the lives of volunteers, other people, and the community. Individuals who accumulated more volunteer hours express gaining more benefits and stay in their volunteer role longer. The benefit of volunteering is increased if volunteers are compensated with a stipend though it is argued receiving compensation may defeat the purpose of altruistic nature of volunteering. In addition, Amin (2009) postulate that volunteering may be perceived as an opportunity to secure low to medium skilled work in the economy.

Transitional Jobs Transitional jobs (TJ) "is a model that provides temporary subsidized jobs and support services to help build the employability of individuals with little or not recent work history" (MDRC, 2013, p. 1). MDRC emphasizes that for ex-offenders, TJ programs provide a source of legitimate income during a critical period just after release. To date, TJ programs for ex-offenders dramatically increase employment rates initially while individuals are working in the subsidized jobs; however, the long-term improvements in labor market outcomes are yet to be determined.

Ex-offender Reentry Risk to Rural Communities

Wodahl (2006) suggests that not only does the ex-offender face barriers for transition into the community but these barriers also present problems or risk to the rural communities to which ex-offenders return. In response, researchers recommend the development of specific policy interventions to meet the unique features of rural life. Wodahl extended this recommendation to include combining research on ex-offender reentry with knowledge from other disciplines such as sociology, addictions, and health care to gain a better understanding of how these obstacles impede transition into rural settings. It is important to note that not all ex-offenders reentering communities pose a threat, and, equally important, it would be naïve to assume that some ex-offenders are without risk. The reader should also consider that national data reveal that although half of ex-offenders that are reincarcerated within 3 years, many are for technical violations of parole conditions rather than for new crimes (MDRC, 2013).

Currently, there is a growing consensus that reentry strategies should be built on a framework known as Risk-Needs-Responsivity (RNR). The RNR approach is designed to help correction agencies identify and target resources to offenders who are at higher risk of recidivism and provide individualized services to address behaviors and circumstances associated with crime. Cognitive behavioral therapy (CBT) is frequently included as a service to address values and thinking patterns that are considered as favorable to crime (MDRC, 2013). The RNR principle when applied appropriately is effective in decreasing the rate of recidivism among offenders inclusive of sex offenders (Marshall & Marshall, 2012). The "risk" principle states that treatment resources should be allocated to those offenders that are high risk, and providers should do more extensive treatment with this population when resources allow. High-risk offenders than low risk tend to do more harm if they recidivate and require more treatment attention. The "needs" principle operates on the premise that treatment providers are to address identifiable risk factors (criminogenic factors) that are able to be addressed and changed in treatment. Addressing these factors will help to prevent reoffending and maximize treatment effectiveness. Responsivity principle requires treatment providers to tailor treatment delivery to the client (e.g., personality, social status, cognitive functioning) referred to as specific responsivity. Treatment provider should also implement treatment approaches shown to be most effective, e.g., CBT across various offender populations (general responsivity), and uses techniques such as role-playing, reinforcement, and modeling (Marshall & Marshall, 2012).

The use of CBT has researched to be effective as a primary form of therapy as well as part of combination treatment strategies (McHugh, Hearon, & Otto, 2010). The use of CBT has been proven beneficial with addressing substance abuse and promotes coping skills while reinforcing the behavior of abstinence (Chandler, Fletcher, & Volkow, 2009). McHugh et al. (2010) proposed the use of CBT in working with individuals with substance abuse problems because it is effective when dealing with co-occurring disorders or dual diagnosis. Coping and communication skills training are important component of CBT for substance abuse, and it incorporates relationship and interpersonal skills building exercises as a method of mending relationships.

Case Study of Henry

Henry is a 48-year-old Latino male who was recently released after spending 12 years in prison for aggravated assault with a deadly weapon and possession of narcotics. Henry grew up in a single-parent home with his mother and four other siblings in a rural area in Virginia. He has not been in contact with them for many years, and his mother has stopped visiting Henry after 5 years of being incarcerated. Henry expressed having three children who are living with their mother who has full custody in a neighboring town, and he is allowed to see them once per month in a supervised visit. Henry lives in a halfway house where he is required to seek employment as a condition of his release, and he earns enough income to buy groceries from doing odd jobs in the neighborhood.

Henry has reported feeling hopeless, restlessness, sleep deprivation, and worthlessness to Dr. Stuart, his rehabilitation counselor, whom he has been seeing for vocational services for the past 2 months because of difficulties finding employment. Henry did not complete high school and had dropped out in the 10th grade but expressed having held several jobs doing retail and landscaping. He has acquired some skills working in the kitchen of the prison for 2 years where he was incarcerated. Henry reports "wanting to get his life back" so he can live independently but finds it difficult to do with a criminal record. He expressed wanting to reconnect with his family and in developing a relationship with his children.

Questions

1. What services could be useful to help Henry achieve full independence?
2. Would you consider Henry to be "job ready" or employable? Why or why not?
3. Are there alternative housing options that would be a good fit for Henry?
4. What theoretical approach would you implement to help Henry?

Summary

Offender populations with disabilities face numerous barriers to community reentry and employment. Often, their readjustment and rehabilitation are hampered by substance abuse and addiction. For many offenders in rural areas, the problems they experienced are complicated further by local stigma and societal attitudes, limited employment opportunities, and housing restrictions. In addition, their disabilities may be hidden, but influence their behaviors, which may be unacceptable to residents and employers in their communities. Counselors working with offender populations in rural areas must be creative in their approach to providing services and identifying community resources. Also, they must work for changes in policies regarding offender status and disability. It is important for counselors to be as persistent as offender populations with disabilities residing in rural areas if a successive outcome is to be achieved.

Resources

Adapting Offender Treatment for Specific Populations (Substance Abuse Treatment for Adults in the Criminal Justice System-SAMHSA): http://www.ncbi.nim.nih.gov/books/NBK64128/

Bellotti, J., Derr, M., Berk, J., & Paxton, N. (2011, March 16). Examining a new model for prisoner re-entry services: The evaluation of beneficiary choice. Final Report: http://www.dol.gov/asp/evaluation/completed-studies/Examining_a_new_Model_for_prisoner_Reentry_Services/FINAL_REPORT_examining_new_model_prisoner_reentry_services.pdf

Community Resources for Justice: http://www.crj.org

Equal Employment Opportunity Commission: http://www.eeoc.gov

Employment Information Handbook for Ex-offenders. U.S. Department of labor: http://www.exoffender.org/up/doc/Exohandbook.prd

National Transitional Jobs Network: http://www.heartlandalliance.org/ntjn

Reentry Policy Council: http://www.csgjustice-center.org/reentry

Reentry Programs for Ex-Offenders by State: http://www.healpforfelons.org/reentry-programs-ex-offenders-state/

U.S. Department of Justice Reentry Site: http://www.esgjusticecenter.org

Learning Exercises
Self-Check Questions

1. What type of gateways are female offenders more likely to enter into criminal behaviors?
2. What are the recommendations for an ex-offender to discuss his or her criminal background on a job application or in an interview?
3. How are rural communities different than urban areas in responding to ex-offenders' reentry into their community?

Experiential Exercises

1. Volunteer or complete a service-learning project in a community-based center for ex-offenders.
2. Interview an ex-offender to identify his or her barriers to reentry in a rural community or small town.
3. Develop a resource manual for counselors and other human service providers working with offender populations in rural areas.

Multiple-Choice Questions

1. Which part of the Americans with Disabilities Act prohibits discrimination against inmates with disabilities?
   (a) Title I
   (b) Title II
   (c) Title IV
   (d) Title V
2. Which of the following do offender populations have lower levels than the general household population?
   (a) Poverty
   (b) Intelligence
   (c) Education
   (d) Children
3. Which of the following has a substantial link to recidivism?
   (a) Lack of transportation
   (b) Inadequate housing
   (c) Substance abuse
   (d) Type of disability
4. Compared to the general population, which types of disabilities are overrepresented among offender populations?
   (a) Attention deficit hyperactivity disorder and conduct disorder
   (b) Reactive attachment disorder and learning disabilities
   (c) Dissociative identity disorder and substance abuse
   (d) Addictive disorders and sleep-wake disorders
5. Which of the following services are not available to offenders in transition to the community?
   (a) Food stamps
   (b) Public housing
   (c) Temporary Assistance for Needy Families
   (d) All of the above
   (e) None of the above
6. Which of the following is an advantage of a full assessment and self-assessment for the ex-offender?
   (a) Gain insight into the behavior of others
   (b) Avoid employment and personal situations for which he or she is not well suited
   (c) Learn how to answer self-incriminating questions
   (d) Learn how to seek support from family members
7. Which of the following reentry strategies is designed to help identify resources for offenders who are at higher risk of recidivism?

   (a) Psychoanalysis
   (b) Risk-Needs-Responsivity
   (c) Risk-Deflation-Inflation
   (d) Trans-theoretical model
8. Which of the following is more likely to be stigmatized for breaking the law?
   (a) Women
   (b) Men
   (c) Adolescents
   (d) Older Adults
9. Which of the following groups is the criminal record penalty substantially greater?
   (a) African Americans and Whites
   (b) Latinos and Whites
   (c) Whites and Hispanics
   (d) African Americans and Latinos
10. Which of the following is a reason that employers are reluctant to hire ex-offenders?
   (a) Number of hours required to work
   (b) Equal opportunity liability
   (c) Potential for liability
   (d) Stereotypes

Key

1 – B
2 – C
3 – C
4 – A
5 – D
6 – B
7 – B
8 – A
9 – D
10 – C

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13

American Indians and Alaska Natives with Disabilities in Rural, Tribal Lands, Frontier Regions, and Plain States

Debra A. Harley

Overview

American Indians and Alaska Natives (AIANs) are younger than the total population on average (Smith-Kaprosy, Martin, & Whitman, 2012). AIANs represent tremendous cultural diversity including tribal affiliation, traditions, languages, geographic location, and acculturation. Given the expansive number of tribes, it is beyond the scope of this chapter to represent such diversity. In addition, it is not the intent of the chapter to subsume the entirety of American Indian and Alaska Natives' identities within the limits of these pages. Rather, the focus is to discuss commonalities that have distinctively shaped the health, including risk and resilience of AIAN, especially those in rural, tribal, and frontier regions. Certain historical trauma, history of circular migration and residential mobility (i.e., travel between urban areas and reservations) (Rhoades, Manson, Noonan, & Buchwald, 2005), lower socioeconomic status, and poor quality of life indicators provide an understanding of the disproportionate rate of disability and chronic illness, high infant mortality rate, prevalence of substance abuse, suicide rate for AIANs, and higher rate of violence (domestic violence, physical and sexual assault) among AIAN women. Although rural and frontier communities are defined elsewhere in this book, the term reservations is defined in this chapter to provide the reader with the definition as recognized by the US government. As of February 5, 2015, the Secretary of Education amended the definition of "reservation" under the regulations governing the American Indian Vocational Rehabilitation Services (AIVRS) program to conform to the Department's current interpretation and practices. The definition is as follows:

> "Reservation" means Federal or State Indian reservations; public domain allotments; former Indian reservations in Oklahoma; land held by incorporated Native groups, regional corporations, and village corporations under the provisions of the Alaska Native Claims Settlement Act; and defined areas of land recognized by a State or Federal Government where there is a concentration of tribal members and on which the tribal government is providing structured activities and services. (Office of the Federal Register, 2015)

Tribal Nations maintain sovereignty status and practice the policy of tribal self-determination, government-to-government relationships, and tribal consultation. The definition of "reservation" has significance in the evolution of disability legislation because it is linked to legislative advocacy. It is important to note that the term American Indians did not appear in the text of the Rehabilitation Act of 1973, and in 1975 there were no provisions for culturally relevant services

D.A. Harley (✉)
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: dharl00@email.uky.edu

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for AIANs in the Rehabilitation Act. It was not until the 1978 Amendments to the Act that the term American Indians was included. By 2014, the term American Indians appeared more than 27 times in the Rehabilitation Act.

The ten largest American Indian tribes are the Navajo, Cherokee, Sioux, Chippewa, Choctaw, Apache, Pueblo, Iroquois, Creek, and Blackfeet (US Census, 2010). Overwhelmingly, AIANs are more heavily concentrated in the western region of the United States (Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming). AIANs account for less than 1% of the US population, which may make them relatively invisible and more susceptible to stereotypes (Bureau of Indian Affairs, 2011). Yet, they are disproportionately represented among those with disabilities, poor health outcomes, and in the mortality rate due to certain types of conditions such as alcoholism, obesity, and diabetes. Characteristics of rural health and social service delivery systems are often distinctly different from urban delivery systems, and across rural, frontier, and territory (RFT) communities, there is considerable variation in health and social service infrastructure (Moulton et al., 2005). In fact, the health status of AIANs has been referred to as national tragedy and an extraordinary challenge (American Health Commission for Washington State, 2010; Cohen et al., 2012; Goins, Bogart, & Roubideaux, 2010; Roubideaux, Zuckerman, & Zuckerman, 2004). Approximately 28 percent of tribal families live at or below the poverty level (Office of Minority Health, 2012). To assist the reader, certain key terms are defined in Table 13.1.

Table 13.1 Terminology

Difference – used as the interpretation of disability
Elder – in the AIAN community denotes a position of leadership, based on experience, spirituality, and community service, rather than on chronological age. (*Note*: older AIANs are frequently referred to as elders)
First people – refers to indigenous people of the land
Indian country – refers to all reservation lands, dependent Indian communities, and all Indian allotments within the borders of the United States. (*Note*: AIANs in urban areas who maintain strong ties to ancestral tribes and lands, Indian country is also considered a "state of mind"). Because AIANs were not confined to reservations before contact with Europeans, many AINAs consider the entire United States to be Indian country and continue to hold sacred many sites that are not on reservations or tribal lands (e.g., the Black Hills of South Dakota)
Native – a collective term to describe the descendants of the original peoples of North America
Tribal members – belonging to a federally recognized American Indian or Alaska Native tribes

Adapted from Lovern (2008)

The American Community Survey (ACS) defines a disability as "a long-lasting physical, mental, or emotional condition" that "can make it difficult for a person to do activities such as walking…or to work at a job or business." Application of this definition means that approximately 23.8 percent of AIANs have a disability (Smith-Kaprosy et al., 2012). It is noted that many Native languages do not have words that translate words such as "disability," "handicapped," or "crippled" (Locust, 1986, p. 14). However, from an anthropological perspective, terms for disability and other related concepts and medical terms do exist in certain tribes (see Ablon, Rosenthal & Miller, 1967; Werner, 1965). It is important to remember that the term disability is culturally laden and may intersect in quite different ways both in a comparison of Anglo to Indian and in comparison among different AIAN tribes and peoples (Schacht, 2001).

Traditional Cultural Values and Strengths

Cultural values have been the hallmark of strength and reliance for AIANs for centuries. American Indians and Alaska Native populations have values, beliefs, and practices that provide structure and guide their behavior. Each tribe's development and culture are influenced by geography, region, climate, and exposure to other tribes. Because it is not possible to include individualized characteristics of the many tribes and cultures of AIAN, generalizations are discussed based on shared commonalities, and the reader is encouraged to assess their applicability for particular AIANs and their circumstances. It is noted that each tribe will have its own perspective on disability. Some tribes do not historically recognize disability as a medically related condition, and others do not have terminology that is most commonly used in Western disability models (Schacht, 2001). Cohen et al. (2012) provide an example of how AIANs may conceptualize the term disability:

> The concept of disability in some AIAN communities may focus on whether the individual is living in harmony or whether the individual is able to fill his/her role in family and community rather than an individual's impairment. Although the term 'disability' is now more commonly used in AIAN communities, its meaning may differ from community to community. (p. 25)

The diagnosis and label of disability applied by non-AIANs may be rejected or considered as irrelevant from the standpoint of AIANs. Disabilities are viewed more as possible variations of the human condition in which a person may need assistance from others. The need for assistance does not equate to a handicap that leads to marginalization or disempowerment. Moreover, the type of assistance needed and how it is given also differs from non-AIANs conceptions of removing barriers (Pengra & Godfrey, 2001).

Moving beyond the expansive heterogeneity of AIANs, a set of cultural values encompasses their ways of thinking and ways of doing (McMaster & Trafzer, 2004). For traditional Native people, the essence of who they are and how they experience life is grounded in a unique relationship between themselves and the tribe. That is, AIANs are social, emotional, historical, and political extensions of their tribal nation (Atkinson, 2004). Today, many AIANs are rediscovering traditional Indian values and implementing them to revitalize their communities. In the following section, similar to other counseling literature (e.g., Garrett & Portman, 2011; Sue & Sue, 2013), the author makes certain generalizations regarding AIANs' values.

Cultural Values AIANs share certain traditional values and communication styles that contrast European American cultures. First and foremost, most AIANs believe in a sacred *relationship with nature* in which human being is considered an interdependent part of the earth, a respect for all living beings and natural resources, and seeks balance and harmony with all living things. Closely aligned with *harmony* are *humility* and modesty. The emphasis is placed on relation rather than domination. Another cultural value that is considered a sign of wisdom and humility is *generosity*. The belief is that "whatever belongs to the individual also belongs to the group and vice versa" (Atkinson, 2004, p. 153). Activities that emphasize cooperation and group harmony are highly valued. Time is interpreted as the here and now, and people do not always live by the clock. The here and now means that where we are *is* where we have come from and where we are going. Native tradition emphasizes a sense of *being* that allows us to live in accord with the natural flow of life-energy. Being means it is enough just to be. The power of being comes from connectedness and belonging, which is at the very heart of where AIANs came from, who they are, and to whom they belong (Atkinson). See Table 13.2 for examples of cultural values.

Certain communication patters of AIANs that contrast those of Euro-Americans may affect interpretation of behavior of AIANs and perceptions of counselors and service providers. For example, AIANs typically avoid eye contact as a sign of respect, whereas Euro-Americans believe that direct eye contact indicates that you are listening and shows honesty and sincerity. Other nonverbal communication patterns of AIANs include minimal body movements, not touching except to shake hands, physical distance, feelings expressed through behavior rather than speech, and controlled emotional expressiveness, except for humor (Atkinson, 2004). Many of these communication patterns can become barriers to service usage and delivery (as discussed later in this chapter).

Family AIAN family systems are complex and frequently misunderstood by human service professionals. The AIAN family structure varies from matriarchal to patriarchal. Unlike the nuclear family structure (and extended or step family structure) to which most human service providers are accustomed, for most tribes, the extended family is

Table 13.2 Traditional cultural values

Sharing – honor and respect are gained by sharing and giving. Keep only enough to satisfy present needs. Possessions are a means for helping others, whereas ownership relates to current possession. Typically, excess goods are acquired to give away during ceremonies
Cooperation/group harmony – work to prevent discord and disharmony and believe that the group and family take precedence over the individual
Living in the present – greater emphasis on the here and now than on the future. Focus on the future is unimportant
Time is relative – be flexible; enjoy the present. Time is always with us. Nonlinear, relative to the activity at hand. The past and future are appreciated, but it is important to *be* than to *become*. Time is considered fluid rather than something to be controlled or managed
Spirituality – the spirit, mind, and body are all interconnected. Illness involves disharmony between elements. Seek harmony with nature for health. Spirituality permeates all areas of AIANs' lives. Spirituality is considered a part of the person and their relationship to all that surrounds them, not a religion
Noninterference – do not interfere with others and observe rather than react impulsively. Try to control self, not others
Speech – speak in a soft, slow, deliberate manner, stressing the emotions more than the content. Speech is usually a secondary expression to behavior
Nonverbal communication – learning occurs by listening rather than talking; delayed auditory response. Silence is especially values, and most AIANs are comfortable with silence. Direct eye contact with an elder is seen as a sign of disrespect
Patience – everything has its place. It is simply a matter of time before a person recognizes where and how things fit together. Everything offers a valuable lesson
Work – unlike the Puritan work ethic, AIANs understand the need for work, but it is interwoven with spirituality, balance, and harmonious lifestyles

Adapted from Atkinson (2004), BigFoot & Braden, (1998), Garrett & Portman (2011), Kohls, (1984), and Sue & Sue (2013)

the basic unit, and children are often partially raised relatives (e.g., aunts, uncles, grandparents) who live in separate households (Sue & Sue, 2013). Multigenerational households are very common in a collectivist culture of AIANs. "The feature of lateral extension into multiple households is accompanied by an additional bonding feature of incorporation by which significant non-kin become family" (Red Horse, n.d.). In addition, it is common practice in the Indian way to claim another person as a relative, thereby making him or her a real family member. The belief is that family is a matter of blood and of spirit (Atkinson, 2004). In rural or reservation communities, family structural patterns vary with geographic and tribal circumstances, and structural complexity is most readily understood in remote areas of tribal homogeneity. In remote areas family structure assumes a village-type configuration with several households in close geographic proximity (Red Horse).

Spirituality Many AIANs do not regard their spiritual beliefs and practices as a religion in the way in which Christians do. The essence of AIAN spirituality is about feelings and connection and forms an integral part of their very being. Spirituality centers on the interconnectedness of the spirit, mind, and body and a balance between these elements to maintain wellness. "The determination of 'normalcy' in health or wellness is dependent on whether or not the individual is in balance with all his or her relations" (Lovern, 2008, p. 5). Lack of wellness is attributed to disharmony in mind, body, and spirit. Disharmony can shift the relation of energies and allows for the occurrence of illness or unwellness. AIAN spiritual and traditional belief is that each individual is responsible for his or her own wellness by keeping him or herself attuned to self, relations, environment, and universe (Locust, 1988; Lovern, 2008). Healing is considered sacred work and in many AIAN traditions cannot be effective without considering the spiritual aspect of the individual. For many contemporary AIANs, it is common practice to use both "white man's medicine" to treat "white man's diseases" such as diabetes and cancer and use Indian medicine to treat Indian problems such as pain or sickness of the spirit (e.g., mental illness, alcoholism). The reader should note that spiritual beliefs of AIANs are determined by several factors including level of acculturation, geographic region, family structure, religious influences, and tribally specific traditions (Atkinson, 2004; see Garrett and Portman, 2011 for additional information).

Old (Elder) AIANs Old AIANs are distinguished from elders in that old refers to chronological age; however, old AIANs may also be elders. Respect for the old is a traditional cultural value and strength of AIANs. Old AIANs are the "Keepers of the Wisdom" and are highly respected because of their lifetime's worth of wisdom and experience (Atkinson, 2004). Old AIANs function in the role of parent, teacher, community leader, and spiritual guide. Old AIANs are expected to pass down their knowledge to younger members of the family. A special kind of relationship based on mutual respect and caring takes place between old AIAN and AIAN children as each child moves through the life cycle from "being cared for" to "caring for" (Atkinson, 2004). Old AIANs are storytellers; the bridge between the past and present; libraries of Indian knowledge, history, and tradition; and role models about the tribe's culture and traditional ways of life (Clark & Sherman, 2011).

Resiliency No agreed upon definition of resiliency exists; however, multiple definitions are offered including "an ability to recover from or adjust easily to misfortune or change" (Merriam-Webster, 2013), "…dynamic process that enable the individual to respond or adapt under adverse situations" Stumblingbear-Riddle & Romans, 2012, p. 2), and "the capacity to adapt successfully in the face of threats or disaster" (Public Broadcast Station, 2013). The most common theme through these definitions is one of adaptation. Spiritual and traditional practices are closely linked with resilience and related to better mental health indicating it may serve as a protective factor (Eastman & Gray, 2011; Garroutte et al., 2003). Other protective intergenerational strategies that promote resilience among AIANs include support networks, oral tradition, humor, tribal identity, elders, language, view of children, family connectedness, spirituality, community control, cultural identification, ceremonies and rituals, and the rainbow (metaphor for Native resiliency) (see Table 13.3) (Gandbois & Sanders, 2009; Goodluck & Willeto, 2009; HeavyRunner & Morris, 1997; Suicide Prevention Resource Center [SPRC], 2013; Wexler, 2011). Just as familial resilience is considered a protective factor for elevating hope and self-esteem, culture has become an important component in the complex relationships between resilience and locus of control (Celik, Cetin, & Tutkun, 2015). Moreover, AIANs resilience is also infused by strengths, abilities, opportunities, and behaviors to handle problems in their own families and communities in the Native American tradition (Goodluck & Willeto, 2009). According to Goodluck and Willeto, resiliency is a trifocal view in AIAN families: resiliency in general, relational worldview (i.e., the mental, physical, spiritual, and contextual), and Native American strengths. "Within AIAN families, resiliency is a particularly complex construct in part due to the importance and extent of family and kinship roles" (Goodluck & Willeto, p. 2).

Table 13.3 Seven themes of the rainbow

Ethos and values – give individuals their sense of belonging to a culture with similar belief systems and practices that guide behavior. *For example*, *respect for others is a paramount value*
Religion and spirituality – was paramount in forming AIAN ideas about resilience. Religion is part of the total circle of life and consistent with their relational worldview. Religious beliefs aid them in difficult times
Language – seen as critical for passing culture, values, and beliefs to children by parents and elders. An understanding of traditional tribal language is important to convey the meaning of stories
Extended family – is the nexus of resilience to express itself. The family, clan relationships, extended family, and other relatives play an important role in how they cope with adversity, stress, and crisis
Responses from the culture – cultural-based practices and tribal programs support members and families to bring out their strengths and to cope with various problems. *For example, drumming, sweat lodges, talking circles, dancing, and medicine man*
Sense of humor – the ability to not take life so seriously and an internal mechanism to help us put things into perspective, cope with difficulties, and bring grace into the world
Moving forward to the seventh generation – is inferred from the Great Law of the Iroquois, which in practice means the AIANs must consider the impact of their decisions on the next seven generations

Adapted from Goodluck and Willeto (2009)

Native Model of Difference The Native model of difference (discourse on disability) is presented to assist the reader to better understand AINAs' view of disability. First and foremost, in light of AIAN worldview, little attention is given to an individual's "disability" or difference. Instead, a person's sameness within the community is what defines the individual (Locust, 1986; Lovern, 2008). That is, a person with a physical, mental, or cognitive disability may be identified as having a difference, but the individual is not classified as "other" based on a disability. AIANs do not see those with disability through the lens of the deficit model. The disability/difference is considered to be one part of the individual's existence, not his or her identity. The value of the individual is not lessened because of the difference. The idea of wholeness is repeated constantly throughout AIAN culture and their understanding of disability, which optimizes the individual's humanity. In addition, even if the individual engaged in behavior that might have resulted in a disability, it is not associated with a moral failing or character weakness (e.g., addiction) in the individual (Lovern, 2008). The reader is reminded that the Native model of difference, like any other perspective, is influenced by rate of acculturation and the extent to which the AIAN retains customs, traditions, and language.

Tribal Government and Rehabilitation Services

In general, states have no legal jurisdiction in Indian country, and therefore tribal and federal law governs in both criminal and civil cases. AIAN nations have tribal sovereignty, a unique relationship by which tribes or nations maintain the right, by treaty, to negotiate directly with the federal government as independent nations. Unlike other ethnic groups, healthcare, education, and social programs for AIANs were bought and paid for with ceded land by treaty. The US Department of Education specifies the mission of the Vocational Rehabilitation Services Projects for American Indians with Disabilities as:

> To assist tribal governments to develop or to increase the capacity to provide a program of vocational rehabilitation (VR) services, in a culturally relevant manner, to American Indians with disabilities residing on or near Federal or state reservations. The program's goal is to enable these individuals, consistent with their individual strengths, resources, priorities, concerns, abilities, capabilities, and informed choice, to prepare for and engage in gainful employment. Program services are provided under an individualized plan for employment and may include native healing services. (US Department of Education, 2016)

As with the purpose of all VR services, the emphasis is on individualized, appropriate, and relevant service that will maximize the strengths, abilities, concerns, and choice of the individual.

Clay, Seekins, and Castillo (2010) assert "disability infrastructure is built upon the existing resources of any community and then extends them for people with disabilities" (p. 143). Regardless of whether urban, rural, or tribal lands, disability infrastructure includes the same categories of services. The challenge for tribal lands is that the quality and access to services is less than adequate. In addition, disability infrastructure in tribal lands and reservations is linked to the economic vitality of the community, which includes natural, physical, financial, human, and social capital (Clay et al.). AIAN communities vary in the degree to which they possess more or fewer of these resources. Because AIAN tribes are not historically and culturally compatible, no one solution can increase opportunities or outcomes for tribal members with disabilities (Clay et al.).

According to Dwyer, Fowler, Seekins, Locust, and Clay (2000), "introducing the concepts of disability and individual legal protections presents challenges that tribal members and leaders must face in order to mutually understand disability within the context of their culture, government, and intratribal relationships" (p. 201). Because tribal governments are likely to resist externally imposed solutions, Dwyer et al. utilized the Tribal Disability Actualization Process (TDAP), which is grounded in theories of participatory action research (Whyte, 1991), to include tribal authorities and leaders across five reservations to develop and implement policy recommendations for tribal members with disabilities. The results of the study provided evidence of the effectiveness of a self-directed approach for developing tribal disability legislation, policies, and programs that are consistent with the Americans with Disabilities (ADA). Dwyer et al. suggest that the TDAP was effective for several reasons. First, it allowed tribal governments to utilize the experience, knowledge, judgment, and wisdom of tribal members to create local solutions that are culturally appropriate and respectful of tribal sovereignty. Second, TDAP allows tribal members to shape their own destinies in ways consistent with their individual cultures, traditions, and beliefs. Finally, it offers a mechanism for the cultural translation and reinvention of ideas. Dwyer et al. consider the TDAP "is a truly rural approach to community development that may have universal application" (p. 212).

Rate of Disability

Overall, statistics are alarming on the health status of AIANs. AIANs experience the highest rate of disability of any minority group in the United States and the lowest opportunity for access to culturally sensitive programs and services of all races (National Council on Disability, 2003a, 2003b; RCT Rural, n.d.; Smith-Kaprosy et al., 2012). According to the 2012 US Census, 16–18% of AIANs have a disability, and more than 25% of those who need care are age 64 or younger. It is estimated that among working age (16–64), the disability rate for AIANs is 27%, as opposed to 18% for the general population, and among those age 65 and older, the disability rate is 57.6%, as opposed to 41% (Clay & Greymorning, 2006). Although AIANs have every type of disability that is found in the general population, there are disabilities that occur more frequently among AIANs.

Over 20 years ago, tribes were surveyed and asked to report on the frequency of disabling conditions. The disabilities most frequently cited among American Indians in the continental United States were diabetes, mental health disorders, and learning disabilities. Among Alaska Natives, mental health disorders, learning disabilities, and deafness or hard of hearing were most frequently reported disabling conditions (Fowler et al., 1994). Today, AIANs are more likely to have a stroke and higher mortality rates from tuberculosis, chronic liver disease (linked to alcoholism), substance abuse, accidents, diabetes, heart disease, obesity, smoking and pneumonia than any other racial and ethnic groups. In fact, AIANs have the highest prevalence rates of diabetes in the world, and diabetes and kidney failure are recognized as an epidemic on reservations and tribal lands (Barnes, Adams, & Powell-Griner, 2010; National Health Statistics Reports, 2010). Among adults aged 18 years and older who smoke, AIANs have the highest prevalence at 29.2% (Centers for Disease Control and Prevention, 2014). The prevalence of disability among AIAN elders is higher than the general population, and functional limitations increase significantly with age and more so for females (Goins, Moss, Buchwald, & Guralnik, 2007). Both older AIAN men and women have the highest prevalence of current smoking, heart disease, and asthma compared to non-AIAN elders (Okoro et al., 2007). In addition, the life expectancy of AIANs is almost 5 years shorter than for the general population (US Commission on Civil Rights, 2004), and they are more likely to die from injuries and chronic diseases than are individual from other racial or ethnic groups in the United States (Indian Health Service, 2017). Likewise, AIAN children display the onset of disability at much younger ages than the general population (Cohen et al., 2012; Okoro et al., 2007). Low income is associated with an increased prevalence of functional limitations, arthritis, diabetes, and stroke (Moulton et al., 2005). See Table 13.4 for types of disabilities most frequently found in AIAN populations.

The discussion of disability in this chapter is primarily focused on adults; however, AIAN children with disabilities represent a growing number. In the school year 2011–2012, the percentage of children and youth served under Individuals with Disabilities Education Act (IDEA) was highest for AIANs at 16%. Among those that received services, the 9% of AIANs who received services for developmental delay under IDEA were higher than the 6% of children overall (National Center for Education Statistics, 2015). AIAN children have the highest preva-

Table 13.4 Disabilities most common in AIAN populations

Overall	Elderly
Alcoholism/drug dependence	Arthritis
Arthralgia	Congestive heart failure
Blindness	Stroke
Diabetes complications	Asthma
Deafness/hard of hearing	Prostate cancer
Emotional/mental health disorders	High blood pressure
Learning disabilities	Diabetes
Orthopedic conditions	Other cancers
Spinal cord injury	

Adapted from Moulton et al., (2005) and National Council on Disability (2003b)

lence of special healthcare needs at 16.6% compared to 14.2% of non-Hispanic white children. AIAN children are slightly overrepresented in the special education population in relation to their percentage of the population, and the majority are educated in the public school system Cohen et al., 2012). Maternal use of alcohol during pregnancy and premature births has been attributed to congenital abnormalities such as fetal alcohol syndrome and intellectual and developmental disorders (IDD). Unfortunately, much of the research has not examined developmental disorders (e.g., autism disorder spectrum) separately. Although the effects of the No Child Left Behind (NCLB) Act remain to be determined, early research suggests that the policy is aversive to maintaining Native culture and effective learning outcomes for AIAN children. According to Balder and Grossman (2009), while teachers essentially supported NCLB's efforts to focus needed attention on students, they also generally agreed the policy forces them to abandon pedagogical practices that they believe to be crucial in educating their children and sustain culture. In fact, teachers believe such restrictions on practices of implementing culturally and linguistically relevant instruction may result in more than academic failure of individual students, but such a curricular shift may be culturally catastrophic.

The reminder of this section will address select disabilities and chronic conditions that are prevalent among AIAN populations. It is important to note that not all disabilities are easily observable or observable at all. When discussing AIANs and types and frequency of disabilities, caution is in order because of their misclassification as either white or Hispanic and the common practice of collapsing existing racial categories into a single group of "other" (Centers for Disease Control and Prevention, 2003; Grandbois, 2005b).

Mental Health Disorders Although tribal differences in the prevalence of certain mental health disorders exist, in general, AIANs have high rates of mental disorders, especially alcohol abuse and dependence, depression, and posttraumatic stress disorder (PTSD) (Beals et al., 2005, see Research Box 13.1). Research suggests that mental illness, mental dysfunction, or self-destructive behavior affects approximately 21% of the total AIAN population (Duran et al., 2004). AIANs' rates of lifetime help-seeking behavior are generally low; they have higher dropout rates and are less likely to respond to treatment. In addition, the terminology of the Diagnostic and Statistical Manual of Mental Disorders (DSM) for diagnosis of mental illness disorder does not correspond with different expression of illness in Native languages. For example, the words "depressed" and "anxious" are not part of Native languages, whereas "ghost sickness" and "heartbreak syndrome" are used to describe symptoms and behaviors that are associated with the DSM diagnoses (National Alliance on Mental Health [NAMI], 2007). Because AIAN culture is holistic in nature, the physical, mental (cognitive), emotional, and spiritual aspects of a person are integrated, and the mind-body separation of western thought is inconceivable (Yurkovich & Lattergrass, 2008). According to Mehl-Madrona (1997), "all illness is an illness of the spirit that manifest itself in the body, mind, and emotions, and we all carry within our souls the capacity to heal ourselves" (p. 17). Many AIANs will seek assistance from designated tribal members who can address disharmony through sacred ceremonies. Others may seek treatment from both traditional healers and healthcare professionals. Ocampo (2010) cautions that the Eurocentric "mental health frameworks, when applied among First peoples, may result in further trauma and perpetuate, rather than address, their problems" (p. 3).

Research Box 13.1

See Beals et al. (2005).

Objective: To compare findings of the American Indian Service Utilization, Psychiatric Epidemiology, Risk, and Protective Factors Project (AI-SUPERPFP) estimates of the prevalence of DSM disorders and utilization of services for help with those disorders in American Indian populations and with the baseline results of the National Comorbidity Survey (NCS).

Method: A total of 3084 tribal members (a Southwest tribe and a Northern Plains tribe) ages 15–54 years living on or near their home reservations were interviewed with an adaptation of the University of Michigan Composite International Diagnostic Interview. The lifetime and 12-month prevalence of nine DSM disorders were estimated, and patterns of help-seeking for symptoms of mental disorders were examined.

Results: The most common lifetime diagnoses in the American Indian populations were alcohol dependence, PTSD, and major depressive episode. Compared with NCS results, lifetime PTSD rates were higher in all American Indian samples, lifetime alcohol dependence rates were higher for all but Southwest women, and lifetime major depressive episode rates were lower for Northern Plains men and women. Fewer disparities for 12-month rates emerged. Both American Indian samples were at heightened risk for PTSD and alcohol dependence but a lower risk for major depressive episode, compared with the NCS sample. American Indian men were more likely than those in NCS to seek help for substance use problems from specialty providers; American Indian women were less likely to talk to non-specialty providers about populations about emotional problems. Help-seeking from traditional healers was common in both American Indian populations and was especially common in the Southwest.

Conclusions: The results suggest that these American Indian populations had comparable, and in some cases greater, mental health service needs, compared with the general population of the United States.

Questions:

1. What mental health disorders were prevalent in American Indian reservation populations?
2. To whom were American Indian women less likely to discuss about emotional problems?
3. Which samples had heightened risk for PTSD?
4. How did the American Indian reservation populations compare to the general population in the United States for mental health service needs?

Research suggests that living in a stressful environment, experiencing traumatic events, historical trauma, high rates of frequent distress, poverty, stigma associated with mental illness, and lack of access to mental health services contribute to negative mental health consequences for AIANs (De Coteau, Hope, & Anderson, 2003; Grandbois, 2005a, b). Events are associated with historical trauma are varied, however, share distinguishing characteristics. First, events are generally widespread among AIAN communities and, at the time of the event, result in many members of the community being affected by the events. Second, historical trauma is experienced at the individual, family, and community levels. Third, collectively the events produce high levels of distress that may translates into generational impact for AIAN populations (Brave Heart, Chase, Elkins, & Altschul, 2011; Cole, 2006; Whitbeck, Adams, Hoyt, & Chen, 2004). According to Big Foot and Braden (2007), the traumatic events endured during previous generations create pathways that increase the risk of mental and physical distress in the current generation and reduce their ability to solicit strength from their indigenous culture or benefit from their natural familial and tribal support system. In addition, many older AIANS (elders) experienced historical trauma (e.g., mistreatment, discrimination, forced relocation, loss of land, loss of people and family, and loss of culture) that may influence their attitudes and perceptions toward mental health services. According to Sotero (2006), the primary feature of historical trauma is that trauma is passed on to subsequent generations through biological, psychological, environmental, and social venues, resulting in a multigenerational cycle of trauma. The psychological concerns of historical trauma for AIANs are manifested as substance abuse (Chartier & Caetano, 2010; National Survey on Drug Use and Health, 2010), co-occurring disorders related to substance abuse and mental health disorders (Abbott, 2007), mood disorders and posttraumatic stress disorder (CDC, 2007; Dickerson & Johnson, 2012), and suicide (CDC, 2007). More often than not, mental disorders coexist with substance abuse disorders and suicide (discussed in the following sections) (Mason & Altschul, 2004).

Stigma of mental illness is prevalent among AIANs, yet the origins and concepts of such stigma remain elusive (Grandbois, 2005a, b), especially considering the embracing nature of AIANs about differences (Native model of difference). Grandbois suggests that existing literature theorizes that the construct of sigma was imposed upon AIANs by the tenets of Christianity, the loss of traditional ways, reculturation (incorporating the ways of the majority), and intermingling among tribal groups which have over time blurred some of the tribal differences. Grandbois emphasized that it is vital for counselors and healthcare professionals to understand the origins and concept of mental illness and stigma as well as the traditional belief systems and principles that are embraced by AIANs. Among AIAN tribes, diversity of beliefs about mental illness is as varied as viewing mental illness as a form of supernatural possession, to an imbalance and disharmony with the inner and outer natural forces in the world to the expression of a special gift to a hopeless state (Grandbois; Thomason, 2011). The different worldviews of AIANs from the majority culture that impact mental care are presented in Table 13.5.

Suicide The suicide rate for AIANs of all ages is much higher than the overall rate in the United States. Suicide rates are particularly high for AIAN males ages 15–24, who account for 64% of all suicides by AIANs (Grandbois, 2005a, b; NAMI, 2007), and suicide is the second leading cause of death among AIAN people age 10–34 (CDC, 2010). There is considerable variation in the suicide rates of AIANs among different regions and different groups. AIANs' most sig-

Table 13.5 Barriers to rehabilitation services for AIANs

Disjointed coordination among agencies	Fragmentation of services across federal agencies and offices
	Lack of coordination and collaboration among federal, state, and tribal programs
	Federal travel and budget limitations
	Advocacy made difficult by multiple education systems (i.e., public, tribal, Bureau of Indian Affairs)
Limited knowledge or understanding about tribal communities	Lack of federal staff knowledge and training for federal personnel on the federal trust responsibility to AIANs and on tribal sovereignty
	Agency staff's fear of the unknown and unfamiliarity with AIAN populations
Limited enforcement of laws protecting people with disabilities on tribal lands	Lack of clarity about legal enforcement options
	Failure to ensure that the national mandate to eliminate discrimination against individuals with disabilities included equal benefits for AIANs with disabilities
Limited local tribal planning to protect and support people with disabilities	Lack of involvement of tribal leaders and tribal members in the design, development, and implementation of programs
	Limited consumer involvement at all levels of policy development
	Difficulties in tribal/state relationships
	Limited tribal awareness and access to new strategies that can better serve people with disabilities
	Historical distrust of the Federal Government by tribal leaders and member

Adapted from National Council on Disability (2003b) nificant risk factors include alcohol and drug abuse, historical trauma, alienation, acculturation, discrimination, LGBT status, community violence, barriers to mental health services access and use, contagion, stigma, poverty, unemployment, exposure to suicide, rural/remote, racism, economic instability, loss or conflict of cultural values and attitudes, media influence, social disintegration, and relationship of risk factors (D'Oro, 2011; SPRC, 2013; Walker, Loudon, Walker, & Frizzell, 2006). For young males, the time of greatest of suicide is from adolescence to adulthood (Middlebrook, LeMaster, Beals, Novin, & Manson, 2001). In an earlier study, Freedenthal (2002) explored predictor factors to determine whether suicidal behaviors differ between reservation and urban AIAN youth and found substantially different factors initiate suicidal behavior between the two groups. Significantly more reservation youth than urban adolescents reported a history of suicidal ideation. The predictors for urban youth suicide attempts included a history of sexual abuse and a friend or family member having attempted or completed suicide. For reservation youth, the predictors included past or current depression, having no father in the home, cigarette smoking, and family history of drug abuse.

Although studies have not connected traditional child-rearing practices to suicide rates among AIAN youth, the awareness of whether those practices are consistent with traditional AIAN methods or in conflict with mainstream methods may help to provide some insight. Traditionally, AIAN children are taught independence by allowing for early personal responsibility. Mainstream culture may interpret early independence as permissiveness. Furthermore, having experience personal freedom at an early age, AIAN youth may have difficulties adjusting to rigid or restrictive rules and boundaries (Brown & Silva, 2011).

Substance Abuse The ability to access information or data about AIAN substance use is restricted because (a) "AIAN reservations are sovereign nations and can in part determine what resources are used for data collection," and (b) "tribal communities are often located in rural areas, it can be difficult to access comprehensive epidemiological data that are consistent for comparison across communities" (Rieckmann et al., 2012, p. 499). Nevertheless, some reliable data is available about substance use among AIAN adults, even if not differentiated by geographic area. AIANs have a long history of alcohol use, and today alcohol abuse and other drug abuse and dependence have produced disruptive effects and yield lifetime rates of substance use disorders (SUDs), especially for AIANs that live on reservations or tribal lands (see Discussion Box 13.1). Moreover, the decimation of SUDs is evident throughout AIAN communities through the erosion of kinship obligations and associated adverse series of suicides, diabetes, accidents, cirrhosis, heart disease, and injuries (Gone & Calf Looking, 2011), and "literally no one is left untouched by the scourge of SUDs" (p. 292). Compared to the general population, more AIANs meet the criteria for alcohol and drug (AOD) use, alcohol disorders, and illicit drug use (i.e., marijuana, opiate pain medications, cocaine, hallucinogens, and stimulants) (Greenfield & Venner, 2012; Substance Abuse and Mental Health Services Administration, 2007). The National Survey on Drug Use and Health (NSDUH, 2010) estimated that the percentage of AIAN adults in need of substance abuse treatment was higher than the national average, yet AIAN adult admissions were lower than other adult admissions. The Treatment Episode Data Set (TEDS) also revealed that although the criminal justice system is the most frequently reported source of referral for all adult substance abuse treatment admissions, AIAN adult admissions are referred by the criminal justice system at a higher rate than other admissions (SAMHSA, 2010).

AIANs are more at risk for alcohol-related consequences compared to the general population. Although the statistics range across various studies, compared to the general population AIANs are significantly more likely to die from alcohol-related deaths, including automobile accidents, suicide, homicide, and chronic liver disease and cirrhosis. AIAN men are more likely than AIAN women to die from alcohol-related causes, and fetal alcohol spectrum disorder (FASD) is considerably higher for AIAN women than non-AIAN even though AIAN women have a lower rate of alcohol use, except binge drinking (NSDUH, 2010; Zahnd, Holtby, & Crim, 2002). Binge drinking is more common among AIANs living in poverty than in the general population living in poverty (NSDUH, 2010; SAMHSA, 2011). Although a greater percentage of AIAN adults abstain from alcohol than non-AIAN adults, their disproportional alcohol-related consequences suggest that AIANs those who do use alcohol consume at exceptionally high levels. Conversely, AIAN youth drink more than non-AIAN youth (NSDUH, 2010). AIAN youth alcohol consumption rates are higher than rates of all substance used combined (alcohol, tobacco, and other drugs when compared to national averages (NSDUH, 2011). According to Stanley, Harness, Swaim, and Beauvais (2014), the prevalence rates of substance abuse for AIAN students living on or near reservations were significantly higher than national rates for nearly all substances, especially for eight graders. Marijuana uses was very high, with lifetime use higher than 50% for all grade groups, and binge drinking rates and OxyContin use were high for AIAN students.

Discussion Box 13.1

The use of alcohol by AIANs has a historical context that is grounded in European colonization. The production of fermented beverages by AIANs was used for ceremonial purposes. For the most part, AIANs were unfamiliar with distilled beverages (more potent alcohol). Distilled beverages were introduced to AIANs and used by European colonists as a medium of trade. No guidelines, laws, or social mores were established in either the distribution or use of distilled beverages. Traders also found that providing free alcohol during trading sessions gave them a distinct advantage in their negotiations (Beauvais, 1998). The outcome was devastating to young AIAN men, who often had control over the furs and skins being traded. Trading for alcohol left AIAN tribes in a state of poverty, which in turn undermined their efforts to cope with European colonialism (Quintero, 2001). Often extreme intoxication was commonplace among colonists, which became a powerful model for social use of alcohol among the inexperienced AIANs. Displays of violent drinking bouts were common among AIANs, colonizing traders, military personnel, and civilians (Beauvais, 1998).

It is suggested that history may have sown the seeds for the prevalence of alcohol abuse in AIANs. A combination of early demand with no regulation and strong encouragement may be the culprit of a "tradition" of heavy alcohol use passed down from generation to generation, which has led to the current high levels of alcohol-related problems (Beauvais, 1998). AIANs on reservations and tribal lands have higher rates of alcohol abuse than their urban counterparts (Gone & Calf Looking, 2011).

1. What extent do historical events contribute to alcohol abuse among AIANs?
2. How did modeling of drinking behavior impact AIAN drinking patterns?
3. How can historical events influence current drinking behavior of AIANs?

As with any population, the reasons for alcohol and other drug (AOD) use are varied; however, causal explanations for AOD abuse for AIANs are highly correlated with genetic and predisposition factors (Ehlers, n.d.), social and cultural influences (e.g., socioeconomic, loss of culture, boarding school experience, colonization) (Westermeyer, 2004), and personal attitudes toward alcohol. Early research suggests that AIAN drinking behavior is often attributed to stress and historical trauma (Belcourt-Dittloff & Stewart, 2000; Mail, 1989). Other explanations of high AOD use among AIANs in rural areas include the harshness of reservation life, isolation and rurality of reservations, modeling behavior (i.e., everyone around you drinks), high unemployment, easy availability and access, and stereotype of the "drunken Indian."

Rieckmann et al. (2012) found that urban AIANs who were polysubstance users or had a history of abuse more frequently reported employment problems, and reservation-based AIANs reported having more severe medical problems and a greater prevalence of psychiatric problems (see Research Box 13.2). Beyond being Indian-owned and not using medications to treat substance use disorders, a comparison of substance abuse treatment for rural programs and urban treatment centers reveals distinct differences. Rural programs are located in a plain state; offer a 28-day residential program including individual counseling, group counseling, and marriage and family counseling; are spiritually based treatment facilities; and admit persons aged 18 years and older who are enrolled in the tribe and have a primary problem with AOD. The urban facility offers a continuum of mental health and substance abuse treatment services including residential family treatment, outpatient services, transitional housing for women and children, and primary healthcare clinic and is not restricted by race or ethnicity or AIAN client's self-identify; length of stay in residential treatment can last up to 6 months, and parents are able to bring their children up to the age of 5 years to treatment (Rieckmann et al.).

Research Box 13.2

See Rieckmann et al. (2012).

Objective: To address the research gap to prepare descriptive analyses of patient populations in the south central plains reservation-based treatment program and urban treatment program in the Northwest.

Method: The Western States Node of the National Institute on Drug Abuse Clinical Trials Network partnered with two American Indian substance abuse treatment programs to compare assess client characteristics, drug use patterns, and treatment needs. Additional sub-analysis examined patients reporting regular opioid use and mood disorders.

Results: Urban clients (n = 74) were more likely to report employment problems, polysubstance, and a history of abuse. Reservation-based clients (n = 121) reported having more severe medical problems and a greater prevalence of psychiatric problems. Client who were regular opioid users were more likely to report having a chronic medical condition, suicidal thoughts, suicide attempts, polysubstance abuse, and IV drug use. Clients who reported a history of depression had twice as many lifetime hospitalizations and more than five times as many days with medical problems.

Conclusions: Findings from this project provide information about the patterns of substance abuse and the importance of comprehensive assessment of trauma and comorbid conditions. Results point to the need for integrative coordinated care and auxiliary services for AIAN clients seeking treatment for substance use disorders.

Questions:

1. How can knowledge of substance use trends and patterns be used to inform treatment?
2. Which psychiatric disorder was elevated in the combined sample of urban and reservation-based AIANs?
3. What does the study confirm about the need for comprehensive intake procedures?

AIAN adults and youth in rural, plain states, and tribal lands or Indian country continue to have higher rates of substance abuse disorders, and substance abuse co-occurring with suicide for youth is extremely high. Gaining insight into the rate of substance abuse among AIANs may be linked to understanding their health behaviors and practices. It is important to note that health behaviors are not merely what people do but how they are impacted by a host of co-occurring factors. The interaction of these factors means that AIANs are simultaneously at risk for all of them, creating a potentially severe network of social and psychological risks that affect their overall health (Native Vision Project, 2012).

Health Behaviors

Health behavior is a particularly important focus for rural populations in general; however, for AIANs understanding the relationship between chronic disease, disability, and healthcare is crucially important. The health outcomes of AIANs are affected by a host of interacting factors including social and cultural barriers, racial and ethnic biases and discrimination, patient health behaviors, environmental factors, delivery of healthcare in a culturally appropriate manner, language, poverty, and low education attainment. In addition, structural barriers such as management of different types of Indian Health Service (IHS) services, geographic location, wait time, age of facilities, provider turnover rates, retention and recruitment of qualified health providers, misdiagnosis or late diagnosis of disease, and rationing of health services adversely impact AIANs' health outcomes as well (US Commission on Civil Rights, 2004). The health status of AIANs is further complicated by a lack of health insurance coverage. Zuckerman, Haley, Roubideaux, and Lillie-Blanton (2004) found that 49% of AIANs have private insurance coverage as compared to 83% for Caucasians. More recent data indicate that for AIANs under age 65, 28.3% are without insurance (National Health Interview Survey, 2014). Often, availability of insurance influences access to and utilization of healthcare services.

AIANs experience disproportionate effects of various diseases that may be linked to risk behaviors such as tobacco use, AOD abuse, high-calorie, high-fat diet, and physical inactivity (Barnes, Adams, & Powell-Griner, 2010; Chino, Haff, & Dodge-Francis, 2009; Cobb, Espey, & King, 2014). The patterns of health risk behaviors for chronic disease for adolescent AIANs living on reservations are consistent with those of adult AIANs. Conversely, health risks for rural, non-reservation AIAN adolescents in the areas of physical health, substance abuse, emotional health, and risk of injury were average or better health habits, with some difference by gender and age (Gray & Winterowd, 2002). Cobb et al. found that these behavioral risk factors were consistent with observed patterns of mortality and chronic disease among AIANs. Because one of the leading causes of death for AIANs is chronic disease, knowledge of family history of these chronic conditions may be important in identifying those at greatest risk for developing the disease (Slattery et al., 2009). As with any individual, knowledge of family history may be important in the health behaviors of AIANs for several reasons: (1) screening recommendations may change based on family health history, (2) determining family history of disease may identify individuals who would benefit the most from adopting a healthy lifestyle or who are at risk because of an unhealthy lifestyle, and (3) educating directly at altering lifestyle characteristics associated with such a disease could reduce an individual's risk of developing it (Slattery et al.; Yoon, Scheuner, & Peterson-Oehike, et al., 2002). In their study of AIANs health behaviors, Slattery et al. found that obesity, physical activity, cholesterol, and perceived health were associated with family history and concluded that individuals with a family history of diseases may have lifestyles that influence their disease risk. Yet, these behavioral risk factors all are amenable to public health intervention (Cobb et al.).

Regardless of whether the health issue is physical or mental, AIANs' help-seeking behaviors emerged as two central categories: health engagement strategy and avoidant strategy (Yurkovich, (Hopkins) Lattergrass, & Rieke, 2012). In Yurkovich et al. study, health engagement strategy was used for the establishment of mental wellness and its maintenance. Health engagement strategy identified seven practices. The first is *spiritual activities*, which included ceremonies related to Native American Indian traditions. The second is *talk with someone*, which included the use of the formal (i.e., professional practitioner) and informal healthcare systems (i.e., elders, family). Third, the practice of *meaningful doing or purpose* is used, in which the purpose for their existence was significantly intertwined with meaningful doing. The fourth practice, *use medication*, had mixed reviews by the participants. On the one hand, participants took their medication because it was helpful. On the other hand, participants experienced difficulty in finding the right medication, and psychiatric visits for medication were sporadic, brief, and focused on medication supervision with little time for talk therapy. The *use of solitude* is the fifth practice and is different from isolation and is perceived as benefiting their ability to deal with stress and creates a healing environment to reduce or control symptoms. The sixth practice, *learning about their illness*, is for participants that had been in treatment programs that focused on teaching them about their disease and how to manage it, expressed feelings of empowerment by this knowledge, and confidence in their ability to stay in balance. The final practice is *performing health physical behaviors* and was recognized as significant to maintaining their wellness because they knew of the connection between their physical state of being and their ability to stay mentally or emotionally balance (i.e., wholeness) (Yurkovich et al.) (see Yurkovich et al. for further explanation).

Avoidant behaviors occurred most often when there had been ongoing unresolved problems. These behaviors were seen as the person's best coping strategy for the emotional level being experienced and the immediate context of the problem. Avoidant behaviors themselves may have been barriers to choosing healthier behaviors (Yurkovich et al., 2012). Avoidant behavioral strategy included five practices. The first avoidant behavior practice is *substance abuse*, which is for the purpose of self-medicating and temporarily eliminating memories of trauma, betrayal, losses (recent and distant), or abuse. The second strategy of avoidance is *suicidal behaviors* related to a sense of hopelessness, poverty, unemployment, and intergenerational depression. The practice of *nonengagement in therapy* is the third avoidant strategy in which participants did not engage in talk therapy for a lengthy time period because of cultural influence, stigma, and lack of understanding its full purpose and benefits. The use of this strategy was also exhibited in their discontinuance of therapy once their crisis or pain was under control. *Denial of symptoms and treatment needs* is the fourth avoidant practice, which supports the cultural beliefs of being strong and independent and fixing it themselves. In addition, cofounding factors such as not knowing what was wrong, how to deal with it, and who to seek for assistance were manifestations of denial. The final practice of avoidant behaviors is *leaving the reservations*. This practice was seen as positive in supporting their sobriety. Leaving the reservation was useful to their maintenance of wellness (Yurkovich et al.).

Another important issue with impact on the health behavior of AIANs is stereotypes of healthcare providers. Bean et al. (2014) found that despite being highly motivated to treat AIAN individuals (and Hispanics) fairly, the majority of nursing and medical students reported awareness of stereotypes associating these patient groups with noncompliance, risky health behavior, and difficulty understanding and/or communicating health-related information. Negative attitudes of healthcare providers are as significant a barrier as the avoidant behavioral strategies of AIANs themselves.

The interplay between barriers to treatment (e.g., access, distance, wait times, personnel shortage) may also influence health behaviors for AIANs. Many AIANs reported having no health plan and no personal doctor, despite living in counties generally served by IHS. The relationship of income to health behaviors was examined by Wolfe, Jakubowski, Haveman, and Courey (2012), and they found that an association with a tribe with Class III gaming leads to higher income, fewer risky health behaviors, better physical health, and perhaps increased access to healthcare. In comparison to the general population, AIANs face many health challenges because of their higher rates of risky health behaviors, poor health status and health conditions, and lower service utilization (Barnes et al., 2010). Moreover, because of the enormous costs of chronic disease and premature death of AIANs, federal and tribal agencies charged with improving the health of AIANs should focus on strengthening primary prevention (Cobb et al.).

Service Utilization and Barriers

In general, persons with disabilities face a multitude of attitudinal, architectural, environmental, cultural, and social barriers. American Indians and Alaska Natives do not always have a central location for services coordination within rural, frontier, and tribal settings (Kauffman & Associates, 2014), which can impact employment, education, housing, healthcare, vocational rehabilitation, and overall quality of life. Tribal communities may lack the infrastructure to support access and accommodation for AIANs with disabilities. In addition, the remote location of most tribal lands and rural and frontier communities do not have access to transportation systems, which results in further decreasing mobility and independence for those with disabilities (National Council on Disability [NCD], 2003a). Often AIANs lack the ability or advocacy skills to navigate programs that have such overlapping responsibilities. Time barriers also exist because many services offer restrictive hours of operation. Broad categories of barriers to services include disjointed coordination among agencies, limited knowledge or understanding about tribal communities, and financial barriers. Limited enforcement of laws protecting people with disabilities on tribal lands and limited local tribal planning to protect and support people with disabilities are also barriers to service utilization. See Table 13.6 for more detail.

Mason and Altschul (2004) identified several barriers to service utilization for AIANs. First, the majority of the IHS budget is devoted to the provision of acute healthcare services, which, in conjunction with the paucity of mental health professionals, result in primary care physicians as the principle source of detection and treatment of mental health and AOD problems. Second, in every IHS service area, the ration of providers to population is well below accepted standards. Third, the IHS' financial resources have not increased relative to inflation in almost four decades. Fourth, there is difficulty in recruiting a sufficient number of primary care physicians, which creates a problem of delivery of services by nonpsychiatric physicians.

AIAN tribes are sovereign governments, and relationships between tribes and states can be strained because of overlapping or conflicting jurisdictions (NCD, 2003a). Federal laws enacted to protect persons with disabilities are not always enforceable against tribal governments because of the sovereign immunity and sovereign status of tribal governments (NCD, 2003b). The poor health of AIANs is further hampered by their inability to access specialty care, in part because of Contract Health Services (CHS) limitations (pays for patient care at non-IHS facilities when services are not available through the local IHS) and lack of other sources of insurance, and a lack of specialty medical services on or near reservations (Baldwin et al., 2008). Although "the Affordable Care Act (ACA) offers important opportunities to increase health coverage and care for AIANs and reduce longstanding disparities they face," half of poor uninsured AIANs live in states not moving forward with Medicaid expansion at this time (Henry J. Kaiser Foundation, 2013, p. 1). The end result is that many AIANs will continue to face the gap in coverage since they will remain ineligible for Medicaid, and those below the federal poverty level will not be eligible for tax credit subsidies for marketplace coverage. It is noted that because Medicaid is a federal program, states must consult with tribes before they can make changes in their Medicaid programs that affect tribal members.

Beyond issues of availability, access, costs, and organizational and infrastructure barriers, many cultural beliefs of AIANs (see Table 13.1) can become barriers to service utilization either because of AIANs' beliefs and practices or service providers' misunderstanding. For example, the emphasis on living in the presence is often

Table 13.6 Worldviews that impact mental healthcare

AIAN	Majority culture
Relations, circular	Linear, point A to B
Holistic	Specialization
Mystical/acceptance	Scientific/verification
Ceremonials/rituals	Psychotherapy
Collectivism	Individualism
Spiritual and balance	Organized religion
Cooperation	Competition
Patience	Assertive
Presented oriented	Future oriented
Herbs, plants, nature	Psychopharmacology
Intuition and vision	Expertise and planning
Wellness, peace, balance	Cure
Being-in-becoming	Doing
Harmony with	Mastery over
Nonverbal	Expressive

Adapted from Burnhill, Park, and Yeh (2009) and Grandbois (2005a, b)

misinterpreted by service providers as indifference and irresponsibility. Often, cultural beliefs and practices in tandem with service providers' lack of understanding of AIAN culture lead to poor communication and misinterpretation of behavior. Although they are not required to accept the Native ontology, epistemology, or social constructs, rehabilitation counselors, healthcare providers, and other human service professionals need to understand and respect the complexities of AIAN cultural practices and their influence to improve client outcomes (Lovern, 2008). In western society when counselors subscribe to the notion that the person of minority status should adapt to that of the majority status and acts on the expectation that the therapeutic process and goals are the same regardless of culture and geography, the outcomes for the client are usually negative. The level of acculturation and the degree to which AIANs identify with the values of the larger society or those of the Native culture should always be considered. In addition, level of acculturation is likely to guide selection of therapeutic interventions and vocational counseling goals (Sue & Sue, 2013). Research suggests that when AIANs feel that their worldview is not respected, they may simply out of services altogether (Simms, 2009; Sue & Sue, 2013; Oetzel et al., 2006).

A continual barrier to service utilization by AIAN communities is their historical cultural mistrust of the outside populations and non-AIAN health services. As a result of this mistrust, many AIANs use traditional healing (NAMI, 2007). Although most AIANs see the potential benefit of counseling only when it is entered into freely and not mandated, resistance to formal treatment is often culturally rooted in concerns and mistrust of past government intrusions into Indian life (Beals et al., 2005; LaFromboise, 1988; Urban Indian Health Institute, Seattle Indian Health Board, 2012).

Cultural values also act as a barrier in the willingness of AIANs to seek help for mental health issues. Typically, AIANs refrain from in-depth, one-on-one self-disclosure within clinical settings. Thus, group counseling is more successful than individual counseling (Lokken & Twohey, 2004). Concerns for privacy is another cultural barrier. Other cultural barriers include a cultural norm of politeness and respect that may result in not directly discussing signs of depression and cultural preferences for restoring well-being (Oetzel et al., 2006). In general, mental illness stigma exists in the United States, and the role of culture is important with regard to stigma, particularly for ethnic minority groups (Abdullah & Brown, 2011).

Repeatedly, research demonstrates that culture plays a crucial role in wellness and significantly affects help-seeking behaviors, treatment regimens, treatment compliance, response to and management of pain, illness, and disability (Cross & Day, 2015; Gray & Rose, 2012; Simms, 2009). Rehabilitation counselors and other service providers will need to find ways to turn cultural barriers into assets in the service delivery process. Clearly, "the strengths and resilience of AIAN people provide opportunities to support positive change and positive community-sanctioned outcomes" (Cross, Friesen, & Maher, 2007).

Recommendations for Effective Vocational Rehabilitation Intervention

In the planning and delivery of rehabilitation services for AIANs, there is no "one size fits all" in how disability is viewed in AIAN communities or how AIAN individuals access services and supporters. In addition, the size and complexity of the particular tribal government and its infrastructure figure into determining the relationship of an AIAN individual and community has to disability and disability-related services and supports (Cohen et al., 2012). Health and human services policy for AIANs comprise "a complex history, and it is a collection of sometimes conflicting federal Indian law, health policy, and intergovernmental relationships…" and "severely underfunded health services" that have led "to severe AIAN health disparities" (Warne & Frizzell, 2014, p. 266).

According to Gray and Rose (2012), "most indigenous approaches for interpersonal interaction begin with the relationship, knowing a person, developing trust, and respect for the individual that fits well with Western interpersonal approaches" (p. 82). Moreover, tribal cultures and values vary greatly from traditional to acculturated, and individual tribal members may fall anywhere along or outside of the continuum between these cultures; it is important for counselors to understand how the AIAN client relates to culture and identity (Gray & Rose). To best provide services to AIANs, counselors and other practitioners must develop an understanding about the cultural practice and beliefs of AIAN populations. In fact, professional license certification organizations have requirements for cultural competency of practitioners when working with diverse populations. Retention in treatment and services is directly related to cultural competence within service provision structures (CI). According to Yurkovich and Lattergrass (2008), "to provide culturally competent care professionals and native healers need to work the integration of spirituality into treatment processes, and advocate the creation and maintenance of healthy environments for improved social opportunities" (p. 437).

Thomason (2011) conducted a survey of mental health and related professionals who have extensive experience with Native Americans to identify practices counselors and psychologists should employ to make sure their work with Native Americans clients is culturally appropriate and effective. The counselors and psychologists were asked to respond to 30 questions, including several closed-end questions and many open-ended questions about how to improve services for AIANs. Some of the general findings were as follows. First, half of the respondents believed that Native American counselors are more effective than non-Natives, while 20% said there is no difference, 18% said it depends on the cultural competence of the counselor, and 12% said it depends on how traditional is the client. Second, the counselor should ask AIANs what they need and how the counselor can help, seek to speak with tribal elders, and offer refreshments. The counseling setting should be inviting with Native art. Third, incorporate spirituality into counseling and/or determine if it is important to the client. Fourth, it is inappropriate for non-Native counselors to use Native health practices because it may be seen as patronizing. Using Native health practices may be look upon favorably if it is done cautiously and if the counselor has been trained in the methods and has tribal approval. Otherwise, it is best to refer the client to a Native counselor or healer. Fifth, psychological testing should be done carefully with due consideration of how the client's culture may affect the results. Finally, in the first session to build rapport, the counselor should (a) welcome the client warmly, (b) offer refreshment, (c) minimize intake paperwork, (d) invite the client to describe the problem or issue from his or her perspective, (e) use self-disclosure to elicit client talk, (f) address the role of culture in the client's life, (g) talk about confidentiality and expectations for counseling, and (h) let the client determine the content of counseling sessions. Overall, the findings suggest that building trust with AIANs is best accomplished through genuine empathy, self-disclosure, understanding the client's acculturation, and cultural competence and involvement in the local tribal communities.

Just as there are guidelines for incorporating AIANs' cultural values and practices into service delivery, essential awareness and sensitivity to myths and stereotypes are equally necessary. For example, the following types of statements are based on stereotypes and should be avoided: (1) can I talk to the *chief* (2) what is your Indian name, (3) ask them if they know an AIAN person that you know, and (4) I have seen "Dances with Wolves" (Brown & Silva, 2011). Too often stereotypes continue to thrive because they are based on historical assumptions about AIANs and a lack of information about AIANs' present lives and circumstances. Counselors and other service providers can defuse stereotypes by checking their own beliefs and unconscious biases.

Although a variety of traditional counseling theories and techniques can be used with AIAN populations, the client-centered model of Carl Rogers (1961) was recommended more often than any other approach (Thomason, 2011). However, several process-oriented aspects of the approach create barriers for effective use with AIANs. First is the importance and centrality of the client-counselor relationship, which questions whether such a one-on-one interaction outside the context of family and community is a pragmatic means of dealing with AIAN clients' problems. The focus on client individuality fails to take into account the role that the client has within the family or community (LaFromboise, Trimble, & Mohatt, 1990). LaFromboise et al. recommend social learning theory deals better with cultural norms because of its focus on teaching appropriate everyday skills and behavior to clients through the use of modeling and rehearsing activities. The strengths of the social learning approach are it is less culturally biased and allows the community to define the community-level target problems to be solved, thus not imposing the standards of the dominant culture. In addition, social learning lends itself to prevention efforts in that it can address potential problems before they develop. Finally, the extensive use of role modeling is a major source of learning in AIAN culture and is both consistent and reinforcing of that extended family tradition (LaFromboise et al.). Other recommended approaches are cognitive behavioral (Jackson, Schmutzer, Wenzel, & Tyler, 2004), motivational interviewing, narrative therapy, and Jungian or "adapted Jungian approach (Duran & Duran, 1995). LaFromboise et al. offer both advantages and disadvantages of behavioral approaches. The advantages of behavioral approaches are in the action-oriented focus on the present rather than on the past, and they lend themselves to implementation by paraprofessionals and in prevention-oriented interventions. A major disadvantage with both behavioral and social learning approaches is the potential misuse when the goals of the client are not the goals targeted for change in therapy or when behavior change processes are controlled by counselors who do not respect the client's goals (LaFromboise et al.).

In an effort to integrate traditional AIAN values and indigenous problem-solving mechanisms into the counseling process, network therapy is similar and consistent with the more traditional AIAN community-oriented interlocking network of family, kin, and friends (LaFromboise et al., 1990). In network therapy (support network), the client's issues are treated within the context of a larger family and community social system, which allows the symptoms to be considered form multiple angles including their functional roles or consequences within a specific system (e.g., workplace, family, community). Network therapy offers the advantages of being applicable in any setting, utilizes natural supports, and is less intimidating than one-on-one client-counselor office interaction (LaFromboise et al.). Refer to the case study to consider the application of various counseling approaches and how to work with the client.

Case Study
The client is a 37-year-old single Navaho woman named JoyWonder, who grew up on a reservation. She is able to read and write and completed high school. Her employment history consists of being a cook and dishwasher in a small nearby town. While at work 1 day, a customer asked her if she ever thought about living off the reservation and moving to the city. The customer worked at the local hospital 30 miles away as a nurse and suggested to JoyWonder that she should consider getting a job as a nurse's aid at the hospital. The customer provided her with information about training.

Upon returning to the reservation that evening after work, JoyWonder presented the idea of moving to the city to her family. She was met with stiff opposition. The family told her of all the bad things that could happen to her in the city. The elders told her that if she moved away, she would be considered dead to the family.

Against the advice of her family and elders, JoyWonder moved to the city. She had lived in the city for 18 months before returning to the reservation for a visit. JoyWonder was confronted with rejection and was told that she now belonged to the white man's world.

Questions:

1. Which counseling approach would you use with JoyWonder?
2. What cultural issues should be addressed?
3. What interpersonal barriers between the counselor and JoyWonder should be addressed?
4. How would you involve the family and community in the counseling process?

Intervention approaches and programs for AIANs with substance abuse problems have been implemented, but have yielded less than satisfactory results (Hawkins, Cummins, & Marlatt, 2004; Whitbeck, Walls, & Welch, 2012). Some researchers have suggested that a lack of compatibility exists between the theories used for prevention programs in AIAN communities and culturally appropriate AIAN worldviews (Champagne, 2007).

Walsh and Baldwin (2015) conducted a systematic review of the literature to assess substance abuse prevention (SAP) efforts for AIAN communities from 2003 to 2013. The focus was to assess program impacts and outcomes, common problematic elements, and theories that guide programming. The authors found that overwhelmingly the majority of programs were targeted toward AIAN youth and adolescents followed by a combination of individuals, families, and communities, with only one designed explicitly for adult women. Program focus was primarily on prevention, and only a few explicitly focused on alcohol use or abuse and rarely did programs address other behaviors. Frequently programs took place as in-school and/or curriculum-based interventions. The methods used to implement the programs varied widely, ranging from a curriculum to life skills-building activities as a main approach. The common cultural elements integrated, adapted, or tailored into the programs included AIAN teachings, involvement of tribal community members or leaders, AIAN core values, and cultural enrichment exercises. Some programs explicitly described cultural elements to include talking circles, AIAN languages, and sweat lodge ceremonies. Almost all of the programs reported positive outcomes, which were categorized as specifically showing increases in knowledge of substance abuse, overall negative attitudes toward substance abuse, refusal skills, general self-efficacy or confidence of participants, negative social normative beliefs toward substance abuse, awareness of substance abuse, decreases or delays in alcohol or other drug abuse, and combination of the previous outcomes. Fewer of the programs (39%) used theory compared to 61% that did not. Of programs that used theory, theories included social cognitive, Cherokee self-reliance, community empowerment theory, cultural compatibility theory, cognitive theory, cultural historical theory, community competence theory, ecological risk theory, and resiliency theory (Walsh & Baldwin). Walsh and Baldwin concluded that to effectively address the high rates of substance abuse of AIANs, there is a need to understand why certain SAP programs work in Native communities. To accomplish this, theoretical underpinnings of program development should be linked to with appropriate measures and ensuring accurate program evaluation. Moreover, an assessment of SAP program evaluations in Native communities, regardless of theory inclusion, is necessary to understand differing cultural practices and their influence on theoretical fit between smaller reservation tribes and non-reservation and urban AIAN tribes (Walsh & Baldwin).

Various models for cultural adaptation have been developed for treatment of AIANs (i.e., BigFoot & Schnidt, 2010). Gray and Rose (2012) proposed an integrated model, the Medicine Wheel Model of Wellness, Balance, and Healing, to demonstrate how any healing needs to incorporate all aspects (the physical, emotional, mental, social, spiritual, values, illumination, humility, acknowledgment, prudence, spontaneity, joy, physical strength, heart, generosity, loyalty, sacrifice, introspection, harmony, ascension, practice, testing, power, perseverance, wisdom, honesty, acceptance, prayer, synthesis, analysis, and interpretation of the elders) in helping the community, family, and individual to maintain balance. These aspects represent contributions from all four directions, east, south, west, and north, and interconnectedness and overlap to perpetuate wellness and balance (Gray & Rose). For cultural adaptation of a treatment approach to treatment, the counselor must also consider aspects of tribal identification, differences in values, and acculturation of the client. With these considerations in a cultural worldview, the appropriate intervention approach can be determined (Gray & Rose). See Table 13.7 for cultural adaptations to treatment when working with adult AIAN clients.

Table 13.7 Cultural adaptations to treatment

When assessing the history and cultural context of the client, it is important to understand his or her perspective and the problem or issue How would the client's problem be explained in his or her culture? Is the problem within the medical, magical, religious, biographical, or educational context? How would the problem be treated by traditional healers within the client's culture? What is necessary to return to a sense of balance?
Work collaboratively with traditional healers if this is important to the client It is good to know what kinds of practices they use Respect that ceremonies and treatments will be kept private within the culture, and it is impolite to intrude without invitation or to pursue information if the client is hesitant to provide it Ask in a way that provides the client an opportunity to give only as much information as he or she may be comfortable providing Understand that food and water are considered medicine in many AIAN cultures because it is an important aspect of keeping life in balance
Understand how the client expresses emotions Asking how men or women in their culture express feelings (e.g., anger, shame, guilt, fear, disgust, joy) gives the emotion a cultural context Follow by asking how the counselor would recognize these feelings in the client's expressions. It may be necessary to access how the emotions may be expressed in their family or tribe
Counselor's attitude and the counseling environment are paramount and should include the counselor's willingness to self-disclose (appropriately) and collaborate with the client while demonstrating regard and respect The counselor should include information about how he or she knows his or her field The counselor's lack of knowledge about the client's culture The counselor's willingness to learn, if the client will teach Regard and respect may be established by asking about traditional greetings, such as a soft, gentle handshake as opposed to the Western firm handshake Check to see if the client has a preferred way to be identified culturally The environment should be physically welcoming (e.g., sage, sweet grass, AIAN art)

Adapted from Gray and Rose (2012)

Before closing discussion of vocational rehabilitation implications for working with AIANs, some mention of attitudes toward work is warranted, especially because employment is the primary objective of vocational rehabilitation services. Traditionally, work for the sake of working was unusual because nature provided for needs. Thus, punctuality is less familiar to

AIANs. Work always has a distinct purpose and is interwoven with spirituality harmony and balance (Brown & Silva, 2011). The cultural values (see Table 13.2) of AIANs may present some obstacles to employment in occupations or settings that require supervision of others or competition. Therefore, the rehabilitation counselor or job placement specialist will need to use AIANs' cultural values as assets in job matching and placement. AIANs on reservations and in rural areas or plain states are generally more traditional and thus less likely to participate in modern industries and economic activities, or less educated and skilled, and thus less able to obtain positions or advance beyond low-level jobs.

Overall, before rehabilitation counselors and other practitioners can employ any type of intervention strategy for working with AIAN populations with disabilities, they should have some prerequisite knowledge that can improve their ability to provide effective and relevant services. In addition to those life issue differences previously mentioned in this chapter, practitioners should operate on the notion that all people deserve respect (Ft. Peck Reservation Focus Group, 1996), contextualize their outreach and education efforts to accommodate cultural differences, recognize the historical dependence on federal programs by AIAN people can be a disincentive to participation in other programs (Brown & Silva, 2011), and identify cultural attributions about the causes of physical and mental health problems and cultural attributions about the solutions to physical and mental health problems (Atkinson, 2004). To facilitate rehabilitation counseling, healthcare, and mental health outcomes of AIANs in rural areas, the counselor must be able to approach services from the worldview of the client and promote informed choice.

Policy and Future Implications

The federal government ratified at least 367 treaties, which signified "trust responsibility" (moral obligation) and legal obligation of the US government to defend tribal treaty rights, lands, assets, and resources, as well as a duty to provide health services. Yet to this day, underfunding and deficiency of resources for the provision of AIAN services are prominent (Prucha, 1994; Warne & Frizzell, 2014). DeJong (2008) suggested that early US government policy and regulations and appropriations for healthcare sat the stage for the adverse consequences of today in AIANs' health and disability status (see Table 13.8 for key laws and policies that affect how AIANs receive health services). Ironically, the failure of the US

Table 13.8 AIAN health policy

Snyder Act (1921) – the first law that allowed Congress to appropriate funds to address AIAN health on a recurring basis. The funding authority for many of the current activities of the HIS is rooted in this act
Transfer Act (1954) – the Indian health program became the responsibility of the public health service under this act. A transfer of health needs to any health facility cannot be made without approval by the governing body of the tribe (tribal sovereignty and tribal self-determination). The authorities were also transferred to the Secretary of Health, Education, and Welfare (now Health and Human Services)
Indian Self-Determination and Education Assistance Act (ISDEAA) (1975) – the basis for authorizing tribes to assume the management of BIA and IHS programs, and it directs the Secretaries of Interior and Health and Human Services to enter into self-determination contracts at the request of any tribe. In terms of health services, any program, function, service, or activity of the IHS can be assumed by the tribe under a "638 contract"
Indian Health Care Improvement Act (IHCIA) (1976) – was instrumental in setting national policy to improve the health of Indian people because the language regarding the responsibility of the US government to improve the health of AIAN people enhanced the intent of previous laws by expanding and describing modern health services. Title V of IHCIA established the urban Indian health programs. The act also included the initial authorization that allowed IHS and tribal 638 health programs t bill Medicare and Medicaid
Affordable Care Act (ACA) (2010) – expanded Medicaid. Requirement of health insurance companies to pay for preventative services and cancer screening
Permanent Reauthorization of the IHCIA (2010) – permanently reauthorized as part of the AC in March 2010. Includes several modifications designed to improve the provision of health services to AIANs. Authorizes Congress to appropriate resources to meet goals

Adapted from Warne and Frizzell (2014)

government to maintain equivalent and relevant expenditures for AIAN services may be as great a contributor to trust issues as cultural beliefs and the level of cultural competence of service providers.

Several policy recommendations have implications for AIAN populations. Duran (2005) suggested, "in this era of evidence-based, reforms to AIAN health policy are essential steps toward remediation and reconciliation practice" (p. 758). Duran's recommendations are offered based on existing facts about AIAN healthcare policies and services. The first fact is that AIAN health professionals provide the most culturally competent care in rural areas. The recommendation is to fund more Native-specific health career opportunity programs. Fact number two is that Native rural and urban communities are poised to conduct community-based participatory research (see Chap. 38) with Native scholars and other enlightened scholars in academia. Thus, the recommendation is to fund more community-based participatory research efforts such as the Native American Research Centers for Health initiatives. The third fact is if given sufficient resources, space, and time, Native communities with Native scholars can propose and test culturally sound and evidence-based public health policy. Clearly, the recommendation is to increase Indian Health Services (IHS) funding to 100% of the level of need to support AIAN self-determination efforts (Duran). The National Congress of American Indians (NCAI, 2012a) strongly recommends that tribes receive direct and adequate funding to provide culturally appropriate services that empower their citizens with disabilities to lead independent lives in their own communities.

The ACA offers opportunities to increase coverage and access to care for AIANs; however, half of poor uninsured adult AIANs live in states not moving forward with the Medicaid expansion at this time and, as such, will continue to face a gap in coverage. States do not have optional authority to require AIANs to enroll in Medicaid managed care organizations (MCO), unless the MCO is operated by the IHS, a tribe, or an urban Indian health program. In addition, the marketplaces provide new coverage options for many AIANs, but only members of federally recognized tribes will receive certain consumer protections (Henry Kaiser Foundation, 2013). Although new and expanded policies exist, the implication is that many AIANs will continue to be underserved.

The Supreme Court ruling in 2012 that the ACA is constitutional sustains permanent reauthorization of Indian Health Care Improvement Act (IHCIA). If the Supreme Court had ruled that ACA was un-severable, which would have made the entire law null and void, that would have erased significant strides made through the IHCIA by (a) terminating ongoing feasibility, (b) obstructing enrollment of tribal employees in the Federal Employees Health Benefits Program, and (c) endangering current implementation efforts by IHS, the Department of Veterans Affairs, and the Department of Health and Human services (NCAI, 2012b). At the writing of this chapter, the United States is in the midst of a presidential election. Although it is not known who will win the presidency, the general consensus is that if the Republican candidate wins, the unraveling of the ACA begins, and "the loss to tribal communities would be tremendous and permanent reauthorization of the IHCIA would be undone" (National Congress of American Indians, 2012b, p. 2).

Summary

AIAN populations represent diverse groups with different, yet overlapping and shared cultural values, beliefs, and practices. They share many of the same historical injustices, healthcare inequities, barriers of isolation, and gaps in resources, especially on or near reservations and in rural areas. In addition, AIAN tribes promote many of the same strengths and resilience for survival. AIAN people are among the most highly vulnerable populations, which increase substantially by economic vulnerability. Understanding how to address the physical and mental health needs of AIANs is best approached from an understanding of their culture. Throughout this chapter great emphasis has been placed on the practice of respectfulness of tribal sovereignty, culturally relevant approaches to services, and involvement of elders in the development of solutions to address the needs of tribal members. In addition, discussion explicitly conjoined healthcare and disability because of their cyclical nature. The future of tribal healthcare and permanent reauthorization of IHCIA is uncertain and more likely will not prevail if the ACA is un-servable.

Resources

American Indian Disability Technical Assistance Center: http://aidtac.ruralinstitute.mt.edu

Consortia of Administrators for Native American Rehabilitation (CANAR): http://www.canar.org

Indian Health Service: http://www.ihs.gov

Native American Advocacy Center: http://www.nativeamericanadvocacy.org

Native American Disability Law Center: www.nativedisabilitylaw.org

National Congress of American Indians: http://www.ncai.org

Office of Minority Health: http://www.omhrc.gov

Understanding Disabilities in American Indian and Alaska Native Communities: Toolkit Guide: www.ncd.gov/rawmedia_resitory/53edc4ab_c8c7_4786_8f04_35a40855075c.pdf

Tribal Epidemiology Centers. (2013). Best Practices in American Indian and Alaska Native Public Health: http://www.glitc.org/forms/epi/tec-best-practices-book-2013.pdf

Learning Exercises

Self-Check Questions

1. How are AIANs disproportionately affected in health outcomes, access to human and health services, and standard of living compared to non-AIANs?
2. How are reservations defined that distinguish them from rural and frontier regions?
3. How do AIANs conceptualize the term disability?
4. Compare the Native model of difference to the medical model of disability.
5. How does historical cultural mistrust of the non-AIAN health services manifest among AIANs?

Experiential Exercises

1. Conduct an interview with a counselor that works with AIAN populations about what type of service delivery barriers he or she is faced with working in Indian land.
2. If available to you, observe a traditional AIAN ceremony. If none is available, identify and watch a documentary about traditional AIAN practices.
3. Develop a training workshop for counselors working with AIAN clients with disabilities in rural, frontier, and territory areas.

Multiple-Choice Questions

1. Which of the following is more common among AIANs living in poverty than in the general population living in poverty?
   (a) Binge drinking
   (b) Cocaine use
   (c) Prescription medication
   (d) Diet pills

2. Which of the following may influence health behaviors of AIANs in rural areas?
   (a) Access to services
   (b) Travel distance to services
   (c) Wait times for services
   (d) All of the above
   (e) None of the above

3. Which of the following is a barrier for AIANs with disabilities on tribal lands?
   (a) Federal government regulations
   (b) Limited enforcement of laws protecting people with disabilities
   (c) Overextension of paternalism from tribal counsels
   (d) Limited interpretation of the Affordable Care Act for people with disabilities

4. Which of the following is a protective strategy to promote resilience among AIANs?
    - (a) Acculturation
    - (b) Preserving the written language
    - (c) Spiritual practices
    - (d) Assimilation

5. Which of the following is a metaphor for Native resiliency?
    - (a) The sky
    - (b) The rainbow
    - (c) The land
    - (d) The water

6. What is the greatest time of suicide for AIAN males?
    - (a) Form middle age to old age
    - (b) From adulthood to middle age
    - (c) From adolescence to adulthood
    - (d) From childhood to adolescence

7. What does the title of "elder" denotes in the AIAN community?
    - (a) A male tribal member with the greatest wealth
    - (b) A female tribal member with the most children
    - (c) A title of Grand Master
    - (d) A position of leadership

8. Which of the following is usually a secondary expression of behavior for AIANs?
    - (a) Direct eye contact
    - (b) Standing tall
    - (c) Speech
    - (d) Emotion

9. Which of the following types of households are very common in a collectivist culture of AIANs?
    - (a) Multigenerational
    - (b) Nuclear family structure
    - (c) Female-headed household
    - (d) Male-headed house

10. Which of the following is considered as creating pathways that increase the risk of mental health and physical distress in the current generation of AIANs?
    - (a) Migration from reservations to urban areas
    - (b) Stigma about mental health
    - (c) Dual diagnoses
    - (d) Traumatic events endured during previous generations

Key

1 – A
2 – D
3 – B
4 – C
5 – B
6 – C
7 – D
8 – C
9 – A
10 – D

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Agricultural, Farm, and Immigrant Workers with Disabilities

14

Glacia Ethridge, David Staten, Kayla D. Goodman, and Delia R. Kpenosen

Overview
The purpose of this chapter is to discuss the characteristics of agricultural, farm, and immigrant workers with disabilities in rural settings and the responsiveness and appropriateness of vocational rehabilitation (VR) services to meet the needs of these clients. This chapter begins with an introduction of the demographics of the agricultural, farm, and immigrant workers, followed by a discussion of the major issues of the chapter and relevant policies that are encountered by this population. Recommendations and/or solutions to VR service delivery will be provided. The chapter will end with future implications and a summarization of the chapter. Throughout the chapter, readers will be provided with instructional features that will enhance knowledge of the readings.

The chapter is comprised of five learning objectives, which include:

(a) Provide demographics of agricultural, farm, and immigrant workers with disabilities.
(b) Identify and discuss the types of disabilities that agricultural, farm, and immigrant workers incur and/or exacerbate as a result of the job.
(c) Identify and discuss the barriers that agricultural, farm, and immigrant workers with disabilities encounter when seeking healthcare treatment as well as state vocational rehabilitation services.
(d) Discuss the relationship between state vocational rehabilitation services and AgrAbility when providing service delivery to agricultural, farm, and immigrant workers.
(e) Provide recommendations and resources to professionals who are working with agricultural, farm, and immigrant workers with disabilities.

Introduction

Approximately 3 million farms and ranches in the United States are operated by 78% of families and farm workers who were born in Mexico and Central American countries (National Center for Farmworker Health [NCFH], 2009), and this number continues to rise (Xiang et al., 2012). The majority of farm workers who migrated to the United States are Spanish-speaking, with less than 20% speaking English having earned only a sixth-grade education. Seventy-two percent of farm workers completed their education in Mexico, while 26% completed their education in the United States (NCFH, 2009). Typically, agricultural, farm, and immigrant workers are

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G. Ethridge (✉) • K.D. Goodman • D.R. Kpenosen
North Carolina Agricultural and Technical State University, Greensboro, NC, USA
e-mail: gethridg@ncat.edu

D. Staten
South Carolina State University,
Orangeburg, SC, USA

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comprised of (79%) men who migrated to the United States compared to 21% of females, who are typically born in the United States (NCFH, 2009).

The highest percentage of immigrant farm workers work in California, Florida, Texas, and Washington (Martin & Jackson-Smith, 2013) and have resided in the United States for more than 10 years with an average age of 33 (NCFH, 2009). Approximately 60% of farm workers are married; however, the majority of agricultural, farm, and immigrant workers who reside in the United States do so without their families (NCFH, 2009). The average income of an individual farm worker can range between $10,000 and $12,000, while the average income for a family can range from $15,000 to $17,000 (NCFH, 2009), leaving many farm workers and their families living below the poverty line. In 2009, approximately 20% of farm workers indicated that they or a family member received a form of Medicaid, WIC, food stamps, and/or TANF (NCFH, 2009) as these workers are often underpaid, uninsured, and employed either seasonally or full-time (Arcury & Quandt, 2007; Field & Jones, 2006; Martin & Jackson-Smith, 2013; NCFH, 2009; Xiang et al., 2012). The rate of employment for those working in agriculture and farming is low, and research has shown that unemployment and underemployment are common for those working in this area (Martin & Jackson-Smith, 2013; NCFH, 2009).

Data Collection of Disability-Related Statistics for Farmers

The US Department of Labor's National Agriculture Workers Survey, the US Department of Commerce's Bureau of Economic Analysis, the USDA's National Agriculture Statistics Service, the USDA's Census of Agriculture, the US Census Bureau's Census of Population and Housing, the USDA's Economic Research Service, and the USDA's Agriculture Resource Management Survey are government agencies that collect data pertaining to farmers. Each agency reports on different aspects of farming (e.g., industry, employment, and farm resources). In 2008, there were approximately 1.3 million self-employed farmers in the United States, 0.42 million unpaid farm labor, and 0.27 million farm service workers (Deboy, Jones, Field, Metcalf, & Tormoehlen, 2008). In 2001, it was found that people between the ages of 15 and 79 "have a disability that affects their ability to perform one or more essential tasks" (Deboy et al., 2008, p. 179). Before delving into the literature, disability will be defined based upon the American with Disabilities Act (ADA) which defines disability as a physical or mental impairment that substantially limits one or more major life activities, a record of such an impairment, or regarded as having such an impairment.

Prevalence of Disability Among Agricultural, Farm, and Immigrant Workers

In general, it is difficult to capture the prevalence of disability among agricultural, farm, and immigrant workers. This is attributed to a lack of research pertaining to this population (Deboy et al., 2008; Field & Jones, 2006), few incentives or interests in understanding the impact of disability pertaining to this population (Deboy et al., 2008), and the lack of general knowledge with regard to immigrant workers (Yakushko, Watson, & Thompson, 2008). Overall, the statistics on the number of disability pertaining to farm-related injuries are limited. The US Bureau of Labor Statistics indicated an approximate 80,000 disability-related injuries, with 5% of these injuries resulting in permanent disability (Deboy et al., 2008). While a definitive number cannot be attributed to the disabilities associated with agricultural, farm, and immigrant workers, the literature does provide some insight with regard to the types of disabilities that are often acquired by this population.

Physical Disabilities

On average, farmers have more physical disabilities than the general population (Field & Jones, 2006). These disabilities include paraplegia, upper limb amputation, quadriplegia and lower limb amputation (Deboy et al., 2008). Other physical disabilities consist of spinal cord, arthritis, cardiovascular, musculoskeletal impairments, and respiratory impairments (Field & Jones, 2006; Oklahoma AgrAbility & DRS AgrAbility Team, 2009). Farm workers may experience specific work-related physical injuries, such as falls, tractor-related incidents, working with animals and mowers, and the use of truck or other work-related machines, which may further increase the likelihood of physical injury (Mwachofi, York, & Lewis, 2009; Myers, Layne, & Marsh, 2009). Tissue damage and hypothermia can also develop for those agricultural, farm, and immigrant workers with disabilities working in extreme colder temperatures (Geng, Stutheridge, & Field, 2013), while heat exhaustion and dehydration impact those farm workers who are employed in extremely high temperatures (Breeding, Harley, Rogers, & Crystal, 2005). In addition to the aforementioned physical disabilities, this population may also develop hearing and vision loss due to the noise level of machines and impact of particles from toxins (Breeding, et al., 2005; Mwachofi, 2007; Mwachofi et al., 2009).

Medical Conditions

When working with crops and animals, agricultural, farm, and immigrant workers are exposed to toxins that are found in pesticides and other hazardous chemicals (Deboy et al., 2008; Martin & Jackson-Smith, 2013). While pesticides are instrumental for crop production, they also produce side effects that can impact farm workers. These side effects include insomnia, dizziness, and numbness. If left untreated, these side effects can lead to more disabling conditions, thus, impacting the farmer's ability to work. Field and Jones (2006) indicated that approximately 5% of non-life-threatening injuries can result in more serious permanent disability. There has been evidence to suggest that there is a relationship between toxins found in pesticides and chronic medical conditions, such as colon, prostate, and skin cancer (Armitage, Mitchell, & Schenker 2012; Deboy et al., 2008; Price et al., 2013). Additional medical conditions that impact agricultural, farm, and immigrant workers pertain to oral health and HIV/AIDS and other sexual transmitted diseases (Arcury & Quandt, 2007).

Major Issues of Agricultural and Relevant Policies for Agricultural, Farm, and Immigrant Farm Workers

It is challenging to determine the number of workplace injuries for agricultural, farm, and immigrant workers with disabilities due the low number of reported injuries, especially for those immigrant farmers who do not possess a US citizenship (Smith, 2012). Often times, immigrant farm workers may not have access to medical care (Price et al., 2013; Smith, 2012). In fact, data has shown farm workers as more likely to be uninsured or underinsured and less likely to seek medical services (Arcury & Quandt, 2007; Oklahoma AgrAbility & DRS AgrAbility Team, 2009; Xiang et al., 2012). For farm workers seeking assistance for workplace injuries, limited access to services is often dependent upon the location of the workplace. For example, farmers with disabilities working in rural areas have unique challenges, such as transportation, health care facilities, health care coverage, and limited resources (Arcury & Quandt, 2007; Hunter, Hancock, Weber, & Simon, 2011; Oklahoma AgrAbility & DRS AgrAbility Team, 2009; Schweitzer, Deboy, Jones, & Field, 2011). There is also a lack of mental health services and physical therapy for farmers working in rural areas (Oklahoma AgrAbility & DRS AgrAbility Team, 2009). Additionally, for farmers who may need immediate medical assistance, it is common for local medical volunteers to provide this assistance (Oklahoma AgrAbility & DRS AgrAbility Team, 2009).

Should a job-related injury occur, agricultural, farm, and immigrant workers may not seek worker's compensation as an option. For example, when the worker happens to be an illegal immigrant, filing for workers' compensation becomes problematic due to their immigration status (Hosier, 2011) and also poses a potential threat for employers who have hired them (Smith, 2012). Additional factors that inhibit immigrant farm workers from seeking worker's compensation is often the result of having a low educational level, not being proficient of the English language, as well as having a lack of knowledgeable regarding their rights as employees or of worker's compensation (Arcury & Quandt, 2007; Hosier, 2011; Smith, 2012; Xiang et al., 2012). Regardless of immigration status, many undocumented agricultural, farm, and immigrant workers have been able to win worker's compensation cases but have been unable to collect payment due to the lack of a social security number, a requirement for claiming benefits (Smith, 2012). Presently, there is not a precise number of immigrant workers that seek worker's compensation or have won cases after acquiring a work-related injury (Smith, 2012), although Xiang et al. (2012) found in their study of immigrant farm workers with disabilities that this population receives worker compensation at lesser rates than US citizens.

The Role of Vocational Rehabilitation Counselors and AgrAbility When Providing Service Delivery to Agricultural, Farm, and Immigrant Workers

Traditionally, the role of vocational rehabilitation (VR) counselors in state agencies is to assist clients in obtaining and maintaining employment. The availability of employment and educational opportunities, lack of resources (e.g., assistive technology), and transportation options can be cumbersome for those VR counselors working in rural areas (Arcury & Quandt, 2007; Field & Jones, 2006; Friesen, Krassikouva-Enns, Ringaert, & Isfeld, 2010; Hunter et al., 2011; Martin & Jackson-Smith, 2013). Thus, rehabilitation counselors working with farm workers in these areas, especially those farm workers who are immigrants to the United States, are met with unique challenges. One such challenge is the language barrier between the client and counselor. As stated previously, the vast majority of immigrant farm workers have limited English proficiency (NCFH, 2009). Because of this, it may be difficult for immigrant farm workers seeking services to understand the role and function of the VR counselor and the services that are provided by state agencies. This coincides with another barrier for agricultural, farm, and immigrant workers with disabilities-eligibility. Traditionally, eligibility requirements for VR services may take months, thus, impacting the time that a worker with a disability can resume working. The length of time that it may take for a client to become eligible for services may be contingent on whether or not a state has an Order of Selection ([OOS]; Mathew, Field, & Etheridge, 2011). Generally speaking, an OOS occurs when a state VR agency anticipates that it will not have sufficient or personnel to provide services to consumers (Mathew et al., 2011). Under this order, clients with the most significant disabilities will receive services first. For immigrant workers with disabilities seeking VR services, establishing eligibility may require additional time and documentation, regardless of whether a state has an OOS in place. Providing evidence of citizenship may be problematic for many immigrant farm workers as oftentimes, they have migrated to the United States for work and are unable to provide proof of residency (NCFH, 2009) which may evoke a fear of deportation (Breeding et al., 2005). Because of this fear, many immigrant farm workers may be reluctant to seek VR services.

A third barrier for rehabilitation counselors working with agricultural, farm, and immigrant workers is having little knowledge regarding the farming profession. In order to better understand the needs of farm workers with disabilities, it is imperative that VR counselors are knowledgeable about the agencies that are familiar with agriculture. An agency that can assist VR counselors working with agricultural, farm, and immigrant workers with disabilities is AgrAbility. This government agency has "the expertise in identifying the technology, adaptations, and modifications which can assist the farmer in returning to work" (Oklahoma AgrAbility & DRS AgrAbility Team, 2009, p. 8). It was "established by the Farm Bill of 1990 and administered by the National Institute of Food and Agriculture (NIFA) under the United States Department of

Agriculture (USDA) to serve farmers with disabilities" (Mathew et al., 2011, p. 95). This agency trains, educates, supports, and provides technical information to farmers with disabilities in addition to serving as "an intermediary between farmer workers who want to return to work after the onset of a disabling condition and VR" (Mathew et al., 2011, p. 94). Given that this agency focuses on the needs of farmers, it is imperative that VR counselors work collaboratively with this agency to ensure that agricultural, farm, and immigrant workers are provided services that are unique to their profession. In fact, Mathew et al. (2011) indicated that when both agencies work collaboratively, there is a higher propensity for a farm worker to return to work.

Discussion Box

Helping Agricultural and Farm Workers with Disabilities Continue to Work in Agriculture/Farm Work

Many farm and agricultural workers desire to return to their farming and agricultural careers even after becoming disabled. In order to fulfill this desire, there would need to be assistive technologies and other resources readily available at these job sites. In efforts to assist farm and agricultural workers, the USDA awarded a $720,000 AgrAbility grant to Michigan State University in 2014 to help farm operators and workers with disabilities. The aim of this grant was to help this working population with disabilities overcome challenges in their farming and agricultural careers. Agriculture is an occupation that holds some of the most disabling injuries as well as the susceptibility to disabling injuries. Because there is such an overwhelming exposure to disabling injuries in farm work, many believe that education and awareness are crucial factors in preventing these types of injuries.

1. What types of assistive technologies do you think could effectively assist a farm/agriculture worker with disability on the job?
2. What else could be done to both educate and prevent disabling injuries from occurring on the job for farm/agriculture workers?
3. Do you think the topic of farm and agriculture workers with disabilities is relevant to the rehabilitation counseling profession? Why or why not?

Recommendations to Service Delivery to Agricultural, Farm, and Immigrant Workers with Disabilities

Mathew et al. (2011) identified four strategies that VR counselors can utilize when working with agricultural, farm, and immigrant workers with disabilities. These strategies include the following: (a) VR counselors should be cognizant of whether an OOS exists in their state as many counselors are not cognizant of this information. (b) VR counselors and AgrAbility personnel should develop a working relationship with one another to improve client success. In this study, 31 AgrAbility personnel revealed that there had been negative experiences and interactions with state VR counselors thus impacting service delivery to clients. (c) It be would be beneficial to hire bilingual staff members who can provide services to clients who have limited use of the English language. Further recommendations to providing service delivery for agricultural, farm, and immigrant workers with disabilities seeking services suggest that VR counselors be more proactive with regard to disseminating information regarding the services they provide as immigrant farm workers may not be familiar with services that rehabilitation agencies provide. Other researchers suggest that VR counselors collaborate with persons working in the allied health field, as these professionals may not be as knowledgeable in working with clients who are immigrant farm workers with disabilities seeking services (Arcury & Quandt, 2007; Hunter et al., 2011). It is also recommended that VR counselors provided multiculturally competent services for agricultural, farm, and immigrant workers, which may include services that consider the role of the family, communication style, and the use of nontraditional interventions (Breeding et al., 2005).

VR counselors have several models to choose from when working collaboratively with AgrAbility, as many states have utilized this agency to serve agricultural, farm, and immigrant workers with disabilities. For example, the Oklahoma AgrAbility has been instrumental in working with farm workers with disabilities and VR agencies in identifying, recommending, and selecting the most cost-effective services. Because many agricultural, farm, and immigrant workers with disabilities' goals are to return to the same employer, assistive technology may be needed for this goal to be reached. AgrAbility specialists who work in this area can also find the most appropriate assistive technology that is needed by the client (Field & Jones, 2006). Another AgrAbility partnership that has been effective is the Kentucky Migrant Vocational Program. This partnership consists of the Kentucky Office of Vocational Rehabilitation, the University of Kentucky Graduate Program in Rehabilitation Counseling, and AgrAbility (Breeding et al., 2005). This partnership has resulted in the dissemination of resources into the communities with agricultural, farm, and immigrant workers with disabilities (Breeding et al., 2005). A final resource that VR counselors can utilize relates to assistive technology. Breaking New Ground Resource Center has a large database that focuses on assistive technology (Field & Jones, 2006).

Research Box

Title: Secondary Injury Potential of Assistive Technologies Used by Farmers with Disability: Findings from a Case Study.

Objective: In order to complete certain tasks, farmers with disabilities use assistive technology, which may cause a secondary injury to the famer. This study was designed to help farmers understand the perception of potential for injuries and the safety measures that may be implemented.

Method: This qualitative study was designed using grounded theory. The focus of this study was the safety aspect of assistive technology used by farmers. This study was conducted using multiple case studies based on the assumption that a variety of the customized, home fabricated assistive technology are likely to have different safety measures depending on the detail of the design, the farmer's experience, the function of the assistive technology, and the environments in which they are used.

Results: The participants in this study had an array of disabilities including spinal cord injury, traumatic brain injury, Parkinson's disease, arthritis, and chronic back pain. The assistive technology observed in this study consisted of the additional steps on tractors platforms on chemical sprayers, modified utility vehicle, persons lift, and harvesting carts that goes over rows of plants. The results of the collected data showed that farmers had a vast of relevant experience in using assistive technology to complete agricultural tasks, of which included fabricating their own assistive technology and other farmers who needed it. Seventeen out of the 19 participants in this study had both designed and fabricated their own assistive technology; however, 9 out of 19 participants indicated that they had experienced secondary injuries; 6 participants reported that they made modifications to prevent further injuries. Although 88% of the participants acknowledged the need for safer practices and technology, only 26% considered it worth the effort to implement them. The results in the study indicates that secondary injury causative factors were a result of (a) the absence of specific features on the assistive technology, (b) the presence of a specific feature on the assistive technology, and (c) inappropriate and inadequate feature on the assistive technology that could cause injury.

Conclusion: Assistive technology and techniques adopted by farmers with a variety of disabilities are unique to their needs.

Questions:

1. Why is it important to consider the safety features for assistive technology when it is used to assist farm workers with disabilities on the job?
2. The results identified causative factors related to secondary injury. What are additional causative factors to consider when working with farm workers with disabilities?
3. The researchers indicated that 88% of participants acknowledged the need for safer practices and technology, while 26% considered it worth the effort to implement them. What reason(s) would participants provide in consideration of implementing assistive technology regardless of the risk factors that accompany using this technology?

Case Study

Rodriguez Martinez is a 50-year-old farm worker who has come to an agency in hopes of receiving vocational services. Mr. Martinez is a native of Puebla, Mexico, who moved to North Carolina at age 15 in efforts of finding a better paying job. He is married with two children, serving as the provider of the household. It was difficult for Mr. Martinez to find employment opportunities because he does not speak English fluently and has a seventh-grade education level. He was able to obtain a job as a farm worker where he was injured, resulting in him being paraplegic. As a result of his injury, he is now unemployed but is seeking to return back to that line of work. Due to the paralysis of his lower extremities, it could be challenging for him to return back to farm work without the proper accommodations and assistive technology.

Mr. Martinez lives in a rural area located in Asheville, NC, where there is a scarcity of vocational agencies. Because he is undocumented, he does not have insurance nor does he have a driver's license. This limits his accessibility to transportation and from being able to seek services outside of his neighborhood. Also, he is limited to the amount of services he can obtain being that he would have to pay out of pocket. Mr. Martinez encountered barriers in receiving workers' compensation because he is undocumented leaving him without a social security number. As a result of his injury and frustrations with seeking services, he has experienced some depressive symptoms leading him to drink more than usual.

As a rehabilitation counselor in training, how would you assist Mr. Martinez in gaining employment in the same line of work? If unable to have him return to the same line of work, what would be your next step(s) in identifying employment opportunities? How would you advocate for Mr. Martinez

Future Implications Impacting Service Delivery

One future implication to service delivery is that both VR counselors and AgrAbility representatives will have a stronger partnership that increases the number of successful employment in efforts to helping him receive the necessary services? In addition to working with Mr. Martinez in exploring employment opportunities, what other services, interventions, and/or treatments would you consider in working with this client?

outcomes for agricultural, farm, and immigrant workers with disabilities. This can be established by having a VR representative on the AgrAbility's advisory board, should one exist (Field & Jones, 2006). Building the partnership between agencies can assist farmers in not only returning to work but also receive the appropriate assistive technology to be efficient in completing job tasks. A second future implication impacting service delivery is the increase of VR counselors' knowledge level of agricultural, farm, and immigrant workers with disabilities, which further increases employment outcomes for this population. A final future implication for service delivery is the potential increase in the number of bilingual counselors to work with agricultural, farm, and immigrant workers with disabilities. This increase will permit this population to be knowledgeable about VR services and their rights as employees.

Summary

Agricultural, farm, and immigrant workers with disabilities face unique challenges when seeking VR services. Having a VR counselor who is knowledgeable regarding the field of agriculture is essential when identifying workplace accommodation. In addition to being knowledgeable regarding these accommodations, it is also imperative for VR counselors to work collaboratively with agencies such as AgrAbility who can provide additional support for farm workers with disabilities. Agricultural, farm, and immigrant workers with disabilities may be unaware of the services that VR and AgrAbility can provide; therefore, it is essential that these agencies disseminate information in the communities where this population resides. Having materials in alternative formats (e.g., Spanish, large print, etc.) will also ensure that agricultural, farm, and immigrant workers with disabilities are equipped with knowledge regarding the various services that are afforded by these agencies and the eligibility requirements to obtain services. It is also essential for these agencies to consider the role of culture as it relates to the service delivery to agricultural, farm, and immigrant workers with disabilities.

Resources

1. U.S. Department of Labor's National Agriculture Workers Survey (NAWS) https://www.doleta.gov/agworker/naws.cfm
2. Toolbox: National AgrAbility Project http://www.agrability.org/toolbox/
3. Reaching Migrant Farm Workers: A Technical Assistance Bulletin for Sexual Violence Advocates and Counselors http://www.ncdsv.org/images/Reaching%20Migrant%20Farmworkers%20Spring%202007.pdf3.pdf
4. Farmworker Justice https://www.farmworker-justice.org/content/workers-compensation
5. Fairness of Farmworkers: A migrant and seasonal farmworker initiative http://www.nationalfarmworkeralliance.org/fairness_for_farmworkers_agenda.html

Instructional Features

Key References and Web-Based Features for Use by Instructors and Students

1. B. (n.d.). Despite Disability, Motivational Speaker Continues Farming. Retrieved September 29, 2016, from http://www.agriculture.com/family/despite-disability-motivational-speaker_327-ar46281
2. Field, W. E., & Jones, J. (2006). Disability in agriculture. In J. E. Lessenger (Ed.), *Agricultural medicine: A practical guide* (pp. 70–80). New York, NY: Springer.
3. http://www.farmworkerjustice.org/advocacy-and-programs/agjobs

4. https://www.dol.gov/general/topic/training/migrantfarmworkers
5. http://www.new-ag.info/en/index.php
6. https://www.youtube.com/watch?v=eTdil6S87lc

Learning Exercises
Self-Check Questions

1. What is the role of AgrAbility in working with agricultural, farm, and immigrant farm workers with disabilities?
2. Why is the collaboration between VR counselors and AgrAbility personnel important to providing services to agricultural, farm, and immigrant farm workers with disabilities?
3. What are factors that VR counselors must consider when establishing eligibility for agricultural, farm, and immigrant farm workers with disabilities?
4. What barriers do agricultural, farm, and immigrant farm workers encounter when seeking worker's compensation?
5. Identify the cultural considerations that VR counselors must factor when working with agricultural, farm, and immigrant farm workers with disabilities?

Field-Based Experiential Assignments

1. Students should take a tour of an agency that provides assistive technology to farmers with disabilities and write a paper that addresses the following: (a) identification of the various assistive technology that can be used by agricultural, farm, and immigrant workers with disabilities; (b) discuss how this technology can be used to assist agricultural, farm, and immigrant farm workers with disabilities; and (c) identify the pros and cons that agricultural and farm workers will encounter when using assistive technology.
2. Students are to identify 1–2 vocational rehabilitation and AgrAbility partnerships that have been effective when working with agricultural, farm, and immigrant workers with disabilities. Students should identify the strengths and weaknesses of each program and provide solutions to enhance the service delivery to agricultural, farm, and immigrant workers with disabilities.
3. Students are to work in groups to develop a toolkit that VR counselors can use to disseminate information to clients who are agricultural, farm, and immigrant workers. Information should include, but are not limited to, the services that VR agencies provide, eligibility criteria, and community resources.

Multiple Choice Questions

1. Which of the following is *NOT* true about immigrant farm workers?
   (a) Immigrant farm workers have been unable to win compensation cases.
   (b) Immigrant farm workers do not have a US social security number, which is a necessary requirement for claiming benefits.
   (c) Immigrant farm workers are reluctant to seek medical attention or workers' compensation when injured due to a language barrier and their educational level.
   (d) All farmers are provided with health insurance, regardless of their immigration status.
2. In order to understand the needs of clients, it is recommended that vocational rehabilitation counselors should ________________________________.
   (a) Have experience working on farms and in agriculture.
   (b) Visit the farm/ranch to obtain a better understanding of the working environment.
   (c) Seek help from other farmers.
   (d) All of the above
3. Which of the following is *TRUE* about typical agricultural, farm, and immigrant farm workers?
   (a) Women farm workers are typically born in the United States rather than their male counterparts.

   (b) Male and females farm workers are mostly born in the United States.
   (c) Most male farm workers are born in the United States.
   (d) All of the above.
4. The role of a vocational rehabilitation counselor and knowledge of AgrAbility in assisting farmers with disabilities to prevent additional stress is to ___________________________.
   (a) Acquire additional knowledge about programs that would assist in the vocational outcomes and successes for agricultural and farm workers with disabilities.
   (b) Utilize vocational rehabilitation services that can assist farmers in managing their stress by learning coping skills and linking them with agencies that could assist with managing any debt-related medical bills.
   (c) Provide funding for farmers with disabilities.
   (d) Both a and b.
5. Which medical condition is common for agriculture, farm, and immigrant workers with disabilities who work in extreme cold temperatures?
   (a) Pneumonia
   (b) Cancer
   (c) Tissue damage and hypothermia
   (d) Insomnia, dizziness, and numbness
6. How does the American with Disabilities Act define disability?
   (a) An individual with a documented disability
   (b) A person with a physical or mental impairment that substantially limits one or more major life activities
   (c) A person who has a record of such an impairment or is regarded as having such an impairment
   (d) Both b and c
7. When researching disability-related statistics for farmers, which of the following government agencies collects this data?
   (a) US Department of Labor's National Agriculture Workers Survey
   (b) US Department of Commerce's Bureau of Economic Analysis
   (c) USDA's National Agriculture Statistics Service
   (d) All of the above
8. Which of the following is a *FALSE* statement regarding the statistics of farmers with disabilities?
   (a) Farmers have more physical disabilities than the general population.
   (b) There is an overwhelming amount of statistics on the number of disabilities and types of workers on farm-related injuries.
   (c) When working with crops and animals, agricultural, farm, and immigrant workers are exposed to pesticides and other hazardous chemicals.
   (d) None of the above.
9. When referring to farmers working in rural areas, there is a lack of knowledge for all of the following EXCEPT:
   (a) Physical therapy
   (b) Mental health resources
   (c) Knowledge regarding disability and treatment
   (d) Rehabilitation
10. When working with pesticides, farmers are often impacted by their side effects. All of the following are side of effects of toxins EXCEPT:
   (a) Nausea
   (b) Numbness
   (c) Insomnia
   (d) Dizziness

Answer Key

1. a.
2. b.
3. a.
4. d.
5. c.

6. d.
7. d.
8. b.
9. c.
10. a.

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15

Sensory Impairments Among Rural Populations in America

Bradley W. McDaniels, Byung Jin Kim, and Debra A. Harley

Overview

Sensory impairment usually refers to blindness or a degree of vision loss and deafness or a degree of hearing loss. Vision impairment may be characterized by symptoms of central vision loss, peripheral vision loss, contrast impairment, glare, reduced depth perception, and blur (Burton, Lee, & Potter, 2016; Corn & Erin, 2010). Hearing loss occurs when there is diminished sensitivity to sounds normally heard, and deafness is a degree of impairment in which a person is unable to understand speech even with amplification (Falvo & Holland, 2018). Although the focus of this chapter is vision and hearing impairment, sensory integration dysfunction (SID) (formerly called sensory processing disorder [SPD]) is mentioned because it is a condition that interrupts sensory signals and interferes with communication. Sensory integration disorder refers to the way the nervous system receives messages from the senses. More specifically, the inability of sensory signals to organize into appropriate responses results in certain parts of the brain being unable to receive the information needed to interpret sensory information correctly. Subsequently, the person exhibits motor clumsiness, behavioral problems, anxiety, depression, and learning difficulties. SID can affect people in a singular sense or multiple senses. Individuals with SID have chronic difficulties processing sensory information, which manifest as highly disruptive to everyday life, safety, difficulty in performing work activities, and difficulty in forming close relationships and regulating emotions (Achieve Australia, 2016; Sensory Processing Disorder Resource Center, n.d.).

In rural areas, people with sensory impairment experience a sense of social isolation, loneliness, and even depression. The sequelae of sensory impairments is similar to what may be seen in more urban settings but is frequently more pronounced among individuals living in rural communities who may lack the resources and means to obtain appropriate interventions and essential supports found in larger cities. Moreover, rural communities typically have a larger number of older individuals who, as research supports, are much more likely to have disabling sensory impairments.

Sensory impairments are increasingly prominent among older adults (Crews & Campbell, 2004; Vreeken et al., 2013; Zambelli-Weiner, Crews, & Friedman, 2012), persons with certain type of diseases (e.g., diabetes), individuals with multiple disabilities including intellectual disability (Fellinger, Holzinger, Dirmhirn, van Dijk, & Goldberg, 2009), individuals living in poverty (Dillon, Gu, Hoffman, & Ko, 2010), people with micronutrient deficiencies (e.g., vitamin A defi-

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B.W. McDaniels (✉) • B.J. Kim • D.A. Harley
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: bradley.mcdaniels@uky.edu

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ciency), and among certain populations such as veterans (Smith, Bennett, & Wilson, 2008), non-Hispanic Whites, and older women (Prevent Blindness America, 2012). Dual sensory loss (DSL) or dual sensory impairment (DSI) has a negative impact on functional ability, health, and well-being and creates a financial burden (Cacchione, 2014; Vreeken et al., 2013). Research suggests vision impairment is associated with increased mortality rates in older adults (Freeman, Egleston, West, Bandeen-Roche, & Rubin, 2005; Karpa et al., 2010), and hearing impairment is linked to the cause of mortality through three mediating variables: disability in walking, cognitive impairment, and self-rated health (Karpa et al., 2010).

In RFT areas, several factors converge to adversely place residents at risk for visual impairment including low educational attainment, high unemployment, limited access to a health-care facility, and lack of comprehensive health insurance coverage (Iezzoni, Killeen, & O'Day, 2006; Nayar, Yu, & Apenteng, 2013). Concomitant risk factors of visual impairments include falls, depression, reduced cognitive function, and various functional limitations (Swenor et al., 2015). In RFT areas, occupational noises, especially in farming and agricultural jobs, can lead to hearing loss. In general, it is difficult to determine the extent of and risk factors for dual sensory impairment in rural areas; however, the general consensus is persons with dual sensory impairment have more difficulty in performing activities of daily living, more depressive symptoms, lower quality of life, and increased risk of mortality in comparison with a single sensory impairment (Ramamurthy, Kasthuri, & Sonavane, 2014).

Learning Objectives

Upon completion of this chapter, the reader should be able to:

1. Understand the challenges of people with sensory impairments living in rural areas
2. Understand the benefits of service coordination for persons with sensory impairment living in rural areas
3. Identify strategies to improve service delivery for sensory impairment in rural areas

Sensory Impairments

Sensory impairments can present at any age and are identified as one of the most frequently diagnosed disabilities for individuals later in life (Brennan, Horowitz, & Su, 2005). Typically, sensory impairments relate to sight and/or hearing loss but, more accurately, are made up of multiple components of the central nervous system and include vision, hearing, touch, taste, smell, movement, and body position (Dunn, Saiter, & Rinner, 2002). Individuals receive information from the environment either through the eyes or ears, which are considered primary pathways for acquisition of information essential to appropriate growth and learning (Dutton & Bax, 2010). Individuals with disabilities, including sensory impairments, are associated with poorer health outcomes, lower educational achievements, and higher rates of poverty related to lower rates of economic participation (World Health Organization [WHO], 2011).

Deafness and Hearing Loss Hearing loss is considered a key public health issue due to its impact on cognitive, social, and physical functioning of those affected (Lin et al., 2013). According to recent estimates, hearing loss is the most common, chronic, disabling condition in the United States (Jantz & Thompson, 2017). Hearing loss affects approximately 48 million (20%) people in the United States and can occur at birth (congenital) or develop at any age (acquired; Center for Hearing and Communication, n.d.). Frequently, hearing loss is the result of both genetic and environmental factors (Williams, 2000). Unfortunately, because prevalence estimates are typically based on self-reported data, when utilizing audiometric testing, the actual numbers may be even higher (Lin, Niparko, & Ferrucci, 2011). Age is the strongest predictor of hearing loss with nearly 66% of individuals aged 70 and older having bilateral hearing loss and roughly 75% having hearing loss in one ear (Goman & Lin, 2016). Hearing loss can, indeed, be life altering and result in a number of sequela (e.g., depression, isolation, withdrawal). Presbycusis, age-related hearing loss, is the most common type of hearing loss and generally affects speech comprehension in both quiet and loud atmospheres (Gates, Beiser, Rees, D'Agnostino, & Wolf, 2002). As a result of even mild hearing loss, individuals may experience impaired verbal language abilities affecting both communication and social connectedness (Agrawal, Platz, & Niparko, 2008).

Hearing loss is typically characterized by type and onset. Hearing loss may also be identified as unilateral or bilateral depending on whether the impairment is in one or both ears. Because an individual can have unilateral or bilateral hearing loss, the degree of hearing loss can be classified as either symmetrical (i.e., the same in both ears) or asymmetrical (i.e., different in each ear) hearing loss. Hearing loss is typically described based on the specific type (see Table 15.1) and time of onset (e.g., prelingual or postlingual). Following the identification of the specific type of hearing loss, audiometric testing ensues to evaluate the severity of hearing loss. The WHO standards are typically used to classify individuals' hearing loss (measured in decibels) on a continuum consisting of mild (26–40 dB), moderate (41–55 dB), severe (71–90 dB), and profound (>90 dB) (Table 15.2).

Table 15.1 Type of hearing loss

Type	Description
Conductive	Reduced hearing ability even though the cochlea is normally functioning results from external ear abnormalities
Sensorineural	Decreased ability to hear resulting from damage or malfunction to inner ear structures
Mixed	A combination of both conductive and sensorineural
Central auditory dysfunction	Hearing deficits resulting from damage or dysfunction in the brain

Note: Adapted from Smith, Shearer, Hildebrand, and Van Camp (2014)

Table 15.2 Severity of hearing loss

Severity	Measurement (Db)	Undetectable sounds
Normal	−10–15 dB	
Mild	26–40 dB	Faucet dripping, leaves rustling, birds chirping, whisper
Moderate	41–55 dB	Light traffic, conversational speech, refrigerator, air conditioner
Severe	71–90 dB	Dish washer, vacuum cleaner, garbage disposal
Profound	>90 dB	Lawn mower, food processor, arc welder

Note: Adapted from Jantz and Thompson (2017)

Blindness and Vision Loss Loss of vision can present individuals with numerous significant changes to his/her life. Moreover, vision loss is associated with a number of negative effects including increased loneliness, clinically significant depressive symptoms, loss of functional independence, and possible suicidal ideation (Carrière et al., 2013; Gopinath et al., 2013) Blindness is defined in several ways. One definition is the inability to see at all, at best, to discern light from darkness. The National Federation of the Blind uses a broader definition, which suggests blindness refers to sight that is bad enough, even with corrective lenses, that a person must use alternative methods to engage in any activity that persons with normal vision would do using their eyes. Yet, the US Bureau of Census question about “significant vision loss” includes both total or near-total blindness and “trouble seeing, even when wearing glasses or contact lenses.” The statutory definition of “legally blind” is that central visual acuity must be 20/200 or less in the better eye with the best possible correction or that the visual field must be 20 degrees or less (National Federation of the Blind, 2016).

The 2014 National Health Interview Survey (NHIS) Preliminary Report (Centers for Disease Control and Prevention) estimated 22.5 million (10%) American adults reported they either have trouble seeing, even with correction, or are blind or unable to see at all. In fact, according to the National Federation of the Blind (2016), assessing national and regional visual impairment for 2013, the prevalence of blindness for the United States was 2.3%, while in rural states like Kentucky, the incidence was nearly 50% higher at 3.4%. Of particular concern, as reported by the American Federation for the Blind (AFB, 2017), the age group most affected by blindness was adults between 35 and 64: those in the most fruitful years of employment. The American Community Survey in 2014 results indicates the prevalence of visual disability for all ages is 7,358,400 (2.3%), of which 6,906,500 (8.6%) are age 16–75 years and older, 3,810,600 (9.0%) are women, 3,095, 900 (8.0%) are men, 3,831,700 (1.9%) are age 18–64, and 3,000,400 (6.7%) are age 65 and older. The breakdown by race or ethnicity reported to have a visual disability is (a) White 5,348,700 (2.3%), (b) Black/African American 1,143,500 (2.9%), (c) Hispanic 1,179,800 (2.2%), (d) Asian 230,400 (1.4%), (e) American Indian or Alaska Native 95,300 (3.8%), and (f) some other race 540,400 (2.2%). The median annual earning for persons aged 21–64 years with a visual disability in the United States in 2013 was $35,800, the median annual household income was $37,500, and the number living below the poverty line was 1,124,200 (30.5%). Persons aged 21–64 years with a visual disability that received SSI benefits in 2014 were 662,000 (17.9%). For working age adults reporting significant vision loss, only 40.4% were employed in 2014 (Erickson, Lee, & von Schrader, 2016). Statistics on mobility issues of persons with visual impairment are more difficult to ascertain; however, Guiding Eyes for the Blind (2015) estimates there are approximately 10,000 guide dog teams currently working in the United States, and only about 2% of all people who are blind and visually impaired work with guide dogs.

More than one-third of adults who are blind live in the South and the rest are evenly distributed in the Northeast, Midwest, and West (Zuckerman, 2004). Zuckerman suggests regional differences influence how these blind adults live. For example:

> Blind men outnumber blind women in the South, while the pattern is reversed in the other three regions. Blind adults are older in the Northwest, more likely to be married in the South, less educated in the South, and more educated in the West. Blind adults in the Northeast (89%) and West (86%) are more likely to live in an urban area than in the South (70%) and Midwest (71%; p. 5).

Vision loss can be attributed to a number of causes, but the most common and preventable predictor is diabetes (19.7%; AFB, 2017). The rate of complications (e.g., retinopathy) associated with diabetes is reportedly higher in rural communities for reasons to be discussed later in this chapter (Hale, Bennett, & Probst, 2010).

Dual Sensory Impairment People who are deaf-blind have a combination of vision and hearing loss. It does not mean a person is fully deaf and fully blind. There are two definitions of deaf-blindness. One is used primarily in education and the other in rehabilitation. In education, deaf-blindness is officially defined as “concomitant {simultaneous} hearing and vision impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness” (34 CFR 300.8 (c) (2), 2006). In rehabilitation, the federal definition of deaf-blind is:

> (A)(i) An individual who has a central visual acuity of 20/200 or less in the better eye with corrective

> lenses, or a field defect such that the peripheral diameter of the visual field subtends an angular distance no greater than 20 degrees, or progressive visual loss having a prognosis leading to one or both of these conditions; (ii) who has chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, or a progressive hearing loss having a prognosis leading to this condition; and (iii) for whom the combination of impairments described in clauses (i) and (ii) cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation; (B) who despite the inability to be measured accurately for hearing and vision loss due to cognitive or behavioral constraints, or both, can be determined through functional and performance assessment to have severe hearing and visual disabilities that cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining vocational objectives (Helen Keller Act, 2011, para A[i]).

In other words, when an individual presents having visual or hearing impairments that effect their daily functioning they are deemed eligible for services. Although individuals rarely present as totally blind and completely deaf, the presence of limitations to both sight and hearing result in compounding difficulties. Dual sensory impairment, like either visual or hearing impairment individually but largely absent in the literature, is associated with functional decline (Brennan, Su, & Horowitz, 2006), loss of social participation (Crews & Campbell, 2004), depression (Hallberg, Hallberg, & Kramer, 2008; McDonnall, 2009), decreased perceived quality of life (Wahl, Heyl, & Langer, 2008), and cognitive decline (Lin et al., 2013).

Barriers in Rural Communities

Considering the challenges associated with hearing and visual impairments for those living in metropolitan communities, the barriers for those living in RFT areas are likely to be demonstrably more evident. As discussed in Chap. 3 of this book, transportation is an unresolved issue in the majority of RFT communities, and the challenges may be even greater for individuals with hearing or vision loss. RFT communities frequently lack the accommodations that allow individuals with disabilities to be able to fully participate in life. In the following sections, specific barriers affecting individuals with visual and hearing impairments will be discussed.

Availability of Care Serving small populations of widely dispersed individuals results in a financial disincentive for specialists, which leads to a greater reliance on generalists and subprofessional staff (Nayar et al., 2013). Compared to the nondisabled population, individuals with disabilities consistently face socioeconomic disadvantages, and in RFT communities, the challenges are likely compounded. Research clearly describes the barriers of the limited availability of primary care and specialist physicians, the absence of appropriate diagnostic services, and the inadequate health insurance coverage, which is severely affected by poverty and high unemployment (Acrury et al., 2005; Goins, Williams, Carter, Spencer, & Solovieva, 2005; Larson & Hill, 2005; Pathman, Ricketts III, & Konrad, 2006). Even for individuals who have health-care insurance, having access to specialists is severely limited. The most likely scenario is for specialists from neighboring metropolitan areas to come into RFT communities to offer services on a limited basis. Additionally, research suggests that primary care clinicians in RFT communities have insufficient knowledge regarding disabilities; there exists a lack of access to appropriate specialists, inadequate continuity of care, and inaccessible information (Iezzoni, 2003; Iezzoni & O'Day, 2006). Because RFT communities face geographical, personnel, funding challenges, and lack a formal health-care infrastructure, many RFT areas are designated as health professional shortage areas (HPSAs) and/or medically underserved areas (MUAs; Pennel, Carpender, & Quiram, 2008). Several explanations have been posited as to the reasons for the health-care disparity: (a) undesirable location, (b) fewer educational opportunities, and (c) financial constraints, which all hinder recruitment and retention of physicians.

As a result of diabetes being more prevalent in RFT communities, specialist services are critical for the prevention and early detection of diabetic retinopathy. In fact, fewer individuals with diabetes living in RFT areas report having received an eye exam in the past year, which correlates with the increased incidence of diabetes among rural residents (Hale et al., 2010). Clearly, routine health care is essential to detect early vision and hearing loss; however, in RFT communities, the limited availability of both primary care and specialty physicians along with poverty and transportation barriers result in significant barriers for residents.

Topographical Inaccessibility Rural residents with disabilities experience many of the same challenges to obtaining health care as nondisabled residents, but often the barriers are compounded due to a sensory impairment of other disability. Due to the fact that many RFT communities lack health-care providers, particularly specialists, residents are required to travel long distances to reach appropriate care. Moreover, due to geographic distance, environmental barriers, inaccessible or nonexistent public transportation, and topography challenges, many RFT residents may not be able to access the necessary health care. Personal vehicles are the main form of transportation for rural residents, but as a result of an individual's sensory impairments, he/she will be precluded from driving and will be responsible for finding alternative transportation. For individuals who are deaf or hard of hearing, getting to the health-care provider may not be the greatest challenge; due to the overall costs, having an interpreter available to assist with communication is not likely.

To assist individuals who have low vision or blindness maintain independence, orientation and mobility training is frequently undertaken to assist individuals with sensory impairments in being able to ambulate and negotiate the environment (Zijlstra, Ballemans, & Kempen, 2012). Generally, orientation and mobility training consists of teaching individuals with vision impairment the use of the identification cane (i.e., symbol cane), which is used to indicate one's low vision and help to navigate one's path (Ballemans, Kempen, & Zijlstra, 2011). Echolocation, a learned skill to allow individuals who are visually impaired to navigate through sound, is frequently used and can become one of the main sources of gathering information from one's surroundings. Moreover, many rural communities do not have crosswalk audible crosswalk signals to alert visually impaired individuals when it is safe to cross the street. For individuals with dual sensory impairment, for example, as a result of the inability to localize sound, individuals using a cane may need to hold up a card signifying a need for assistance when crossing the street.

Although orientation and mobility afford a certain degree of freedom for individuals with vision impairments, rural communities frequently lack of sidewalks, curb cuts, paved roads, and cross walks negatively impact mobility. Often, the limitation on mobility ushers in a certain degree of isolation for these rural residents. Refer to Chap. 3 for a more detailed description of the topographical, geographical, and infrastructure barriers in RFT areas.

Technology Almost everyone uses some form of assistive technology (e.g., calculator, cell phone, computer). To garner an understanding of exactly what is meant by assistive technology (AT), having a working definition would be prudent. Blake and Bodine (2002) informally define AT as any tool, device, or machine used to complete a task. A more formal definition is proffered in the Assistive Technology Act of 1998:

> Any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities (Sec. 3(a)(3)).

Therefore, any device or technology that can assist an individual who is visually or hearing impaired falls into the aforementioned definition. Clearly, the availability of various assistive technology devices is critical to afford individuals with sensory impairments the opportunity to fully participate in daily activities. As technology continues to advance, new and improved devices are entering the market, which increases functioning and provides more options for those who require assistance. One of the many challenges surrounding the availability of services to individuals who live in rural communities is accessibility and affordability. Although there are some AT devices that are less expensive, there is usually a positive association between quality and price. For individuals who experience dual sensory impairment, typically either hearing or vision is better than the other, and the decision regarding appropriate AT devices will follow accordingly. A list of devices available for individuals who are hard of hearing or deaf and those with vision impairments is contained in Tables 15.3 and 15.4, respectively. For a more detailed description of assistive technology refer to Chap. 4.

Legislation Individuals with vision and/or hearing impairments are fully covered by the Americans with Disabilities Act of 1990 (ADA). Several parts of the ADA were enacted to specifically address individuals with "communication disabilities." Title II of the ADA dealing state and local government entities and Title III, which addresses business and nonprofit organizations that serve the public be equipped to communicate effectively with individuals who have communication difficulties (e.g., vision or hearing loss). These accommodations include what are termed "auxiliary aids and services" (e.g., qualified reader, audio recording of printed information, interpreters, captioning). Through the amendment of the Communications Act of 1934, specific language pertaining to telecommunications was added under Title IV (sec 255) of the ADA, which mandated the availability of relay services nationwide. As a result of Title IV, law mandated that relay services be functionally equivalent between those who are deaf or hard of hearing and those who are not. There exist four specific requirements for relay services (a) relay services must be available 24 hours per day, (b) no restrictions on length or content of calls, (c) maintenance of confidentiality of relay operators, and (d) same rates for relay services as typical service calls (Strauss, 1991). For a detailed discussion of the ADA, see Chap. 31.

More recently, additional legislation has been passed to update the nation's telecommunications protections for individuals with disabilities. The Twenty-First Century Communications and Video Accessibility Act of 2010 (CVAA). The CVAA was passed to ensure additional safeguards for individuals with disabilities to continue to be able to access technology in the internet-based and digital communication age (e.g., broadband, mobile communication). There are a number of provisions contained in the CVAA, and several of the more pertinent specifications will be discussed. The CVAA is composed of two main titles: Title I addresses communication access and Title II deals with internet and television programming. Under Title I, the law requires that:

(a) All newly manufactured telephones are compatible with hearing aids.
(b) Relay services are available to all individuals with speech or hearing impairments and extends to those entities providing IP-enabled communication.
(c) Internet-based communication technologies (equipment, services, and networks) must be accessible to individuals with disabilities, unless an undue hardship would result.
(d) Individuals with disabilities are specifically eligible to receive universal service support through both granting the FCC the authority to designate broadband services needed for communication under existing universal service programs and the authority to designate those entities who make specialized equipment eligible for universal service support.
(e) For establishment of an emergency access and real-time text support network that ensures that those who rely on text as a primary means of communication have equal access to emergency services.

Title II, which addresses video programming, has several provisions including (a) video programming guides and menus designed to make video guides, menus, and controls accessible to those who are visually impaired; (b) closed-captioning decoding and video description capa-

Table 15.3 AT options for hard of hearing/deafness

Device	Description
Practical devices	
Baby crying signaler, carbon monoxide detector, doorbell signaler, smoke alarm signaler	All of these devices offer a load tone, flashing lights, and/or vibrations to signal the individual
Telecommunication	
Amplified ringers and telephones	Provides increased volume
TTY/TTD	Utilizes a keyboard and visual display to allow users to communicate
Video phone	Uses a video connections to allow users to communicate through sign language
CapTel	For people who are unable to hear over the telephone but prefer to use their voice to communicate. CapTel calls also must be made through a relay service. This connection allows the person with the hearing loss to speak to the other party and read their incoming message on the telephone's display screen. Today, many people are using CapTel
Assistive listening devices (ADLs)	
Hearing aids	Continue to be one of the most widely used ADLs. There are a wide variety of styles and tremendous variability in quality
FM system	The speaker wears a compact transmitter and microphone, while the listener wears a portable receiver
Infrared system	This wireless system transmits sound via invisible light beams with the volume controlled by the user

Note: Adapted from Minnesota Department of Human Services Online (2013)

bility, which requires that all devices that receive programming over the internet have closed-captioning and that all devices be able to transmit and deliver video descriptions; and (c) improved user interfaces require that all devices that receive or display video programming are accessible by individuals with disabilities (e.g., controlling volume, selecting programming) as well as a conspicuous means of accessing closed-captioning.

Table 15.4 AT options for visual impairment

Device	Description
Video magnifiers	Also referred to as close-circuit TV (CCTV). Uses a stand-mounted or handheld video camera to project a magnified image onto a monitor or TV (cost $400–$4000)
Braille displays	Technology provides access to information on a computer screed in braille (cost $3500–$15,000)
Braille printers	Provides a braille hardcopy of information from computers (cost $1800–$5000)
Optical character recognition system	Allows users to scan printed text, which is then spoken back in synthetic speech (cost $1300–$5500)
Speech systems	Converts information from a computer into synthesized speech (cost up to $1100)
Screen magnifiers and phone apps	Many of the new phone apps allow for greater functionality with magnification, currency recognition, and more

Note: Adapted from American Federation for the Blind (2017)

Although these provisions are aimed at the improvement of accessibility of telecommunications for individuals who have sensory impairments, if individuals live in rural areas where Internet and broadband access is scarcely available, little effect may be realized. One of the barriers apparent in rural communities is the transmission of information to residents. Many may not be aware of what is available to them nor have the necessary supports to ensure that the law is effectively providing meaningful improvements. How individuals become informed and access available services is one of the most salient issues needing attention.

Rural Outreach

One of the challenges is how to effectively and efficiently ensure that those living in rural communities have both knowledge about and accessibility to necessary services and AT to allow them to fully participate in the community. As has been demonstrated throughout this chapter, there are numerous barriers preventing the acquisition of available services. Addressing the obstacles faced by individuals living in rural communities will, indeed, require the concerted efforts by local, state, and federal legislators. Overcoming the economic factors, provider availability, educational shortcomings, and geographical isolation are critical factors affecting the delivery of care.

The *Institute of Medicine (IOM) Rural Health Report* (2006; Mueller et al., 2006) asserts rurality or remoteness of location should not be a barrier to access of quality health care. The IOM report includes program recommendations in the areas of developing the rural health workforce, building rural quality improvement infrastructure, financing rural health care, and furthering information technology implementation and utilization. An important consideration to capitalize on recommendations to improve rural health care is an appropriate degree of coordination and recognition of what is working currently and what requires new initiatives (Mueller et al., 2006).

Consider the case of Sydney, a 16-year-old student with a hearing impairment. She presents with several challenges that cut across her functioning in several settings. Review the case of Sydney and examine how living in a rural area may have added to or intensified barriers for her in school, social, and family functioning.

Strategies for Service Delivery One of the solutions considered for bridging the gap between urban and rural health care is telehealth. Many specialties have effectively adopted telehealth as a feasible alternative to face-to-face office visits. One of the major barriers to telehealth in many rural communities is the availability of broadband Internet access. The congressional report of *Broadband Internet Access and the Digital Divide: Federal Assistance Programs* indicates there are nearly 19 million Americans who do not have access to fixed broadband and 14.5 million live in rural areas (Kruger & Gilroy, 2016). For those areas where broadband access is available, telemedicine screening for diabetic retinopathy has been demonstrated to be both effective and cost-effective, eliminating many of the barriers to care (Yogesan, Constable, & Chan, 2002). Technology should serve as a means to increase

Discussion Box 15.1

Sydney is a 16-year-old high school student living in a rural community in eastern Kentucky. She was born with congenital hearing loss and has severe hearing loss (71–90 dB). Although as a teenager Sydney has a diagnosis to explain her hearing loss, for the majority of her schooling, neither her family nor the school knew about her challenges. In grade school, Sydney performed poorly on her assignments, and both her parents and teachers intimated that she was not applying herself. After a couple of years, it was suggested that Sydney may have a learning disability and was placed in special education classes, which failed to improve her work. She was described as shy and uninvolved with her classmates and was referred for counseling. In counseling, Sydney told the therapist that she was embarrassed that she could not hear teachers or classmates and chose to avoid situations where conversations were necessary. Through her work with a therapist, Sydney's hearing impairment was discussed and hearing aids were recommended. Through Medicaid, Sydney was able to receive hearing aids, but they were of poor quality and only amplified sounds – all sounds. Therefore, even when Sydney was wearing the hearing aids at school all of the background noise continued to interfere with hearing the teachers. Although the city was only about 90 min away, Sydney's family only had one car, which was not very reliable. Through the help of a local church, Sydney was able to secure transportation to the city for a thorough evaluation. The audiologist determined that Sydney needed higher-quality hearing aids, but they would cost nearly $1000.

1. What type of skills do you think would have helped teachers to recognize Sydney's hearing loss?

2. How could have coordinated efforts across the school system, health-care providers, and her family helped to identify Sydney's hearing loss? What recommendations would you make to the various service entities in the rural area working with Sydney?
3. What issues could have contributed to Sydney's hearing loss when she was a young child? How could this change if primary care providers in rural areas always conduct hearing tests?
4. What difference would it make to have the appropriate hearing aids at an early age made in Sydney's life?

access to and to improve health-care quality and in itself is not the measure of success. The end results are "patient safety, health care quality, and improved quality of life for rural people and places" (Mueller et al., 2006, p. 14). An addition to the use of technology for actual patient care is the importance of adapting information systems to the scale of rural health-care providers. The IOM suggests avoiding super imposing an urban system in rural settings, rather, to design appropriate information systems to interface with urban information systems to promote ease of communication and patients transitioning between care delivery sites.

There are several practices that may provide greater availability of specialty care in rural areas. One is increasing financial incentives for health-care providers serving in underserved areas. Many rural communities have had success in attracting new providers by partnering with medical schools and offering forgiveness of student loans for providers who practice in rural communities. In addition to using financial incentives to recruit new providers, The IOM report emphasizes the need to sustain a high-quality health-care delivery system in rural areas. Thus, two critical elements to this end are (a) financing must be sufficient to sustain the system, and (b) payment systems (e.g., bonus payments, cost-based payments) must support innovations that improve quality in health-care delivery (Mueller et al., 2006).

Another practice is increasing transportation options in rural areas can affect patients being able to access providers in neighboring communities. This can potentially be accomplished through a voucher system or community organizations assisting with ridesharing. Transportation options become increasingly important in rural areas not only because of geographic distance but also extreme weather conditions and environmental and climate barriers (see Chap. 33).

Education of community health-care workers in the identification of visual and hearing changes is yet another practice that may help to get patients to a specialist before irreversible damage occurs. Community health-care workers can play a critical role in both screening and appropriate management of sensory impairment. This idea is best represented through the coordination of accessibility across the continuum of care. Because of the limited access to specialists in rural areas, those working in the primary care setting need to be equipped to effectively address a variety of issues and make appropriate referrals. Moreover, all of the providers involved in an individual's care need to communicate about the treatment plan and assessments of needs. Often, in rural areas and because of geographic variation, lack of access to a specialist such as an audiologist or ophthalmologist may necessitate the functions and services of the care provider be integrated in the context in which the user of health-care services lives (Green, 2004) rather than by the credentials of the person providing the services.

Smith, Shepherd, Jepson, and Mackay (2016) found a support center for people with sensory impairment living in rural areas provided one way of ameliorating health inequalities in this population. Following the sensory center assessment and support, some patients identified ways in which interventions had reduced their sense of isolation, increased sense of self-esteem and safety, and supported greater functional independence in their own homes. Clearly, such support was about more than medical intervention.

Summary

Visual, hearing, and dual sensory impairment present numerous challenges for individuals in all areas of society, but in RFT communities, the barriers are significantly more pronounced. Both visual and hearing impairments are linked to reduced functioning and negatively impact one's participation in desired and necessary activities as well as quality of life. Due to the lack of eye care specialists practicing in RFT areas, the unavailable and/or inaccessible transportation options to allow individuals to commute to receive appropriate care, the persistently low socioeconomic status resulting in part from high unemployment rates, and lack of comprehensive health insurance coverage, individuals in RFT communities have difficulty accessing and receiving the services needed to afford them the opportunity to be as fully functioning as possible. Clearly, more research needs to be undertaken to effectively ensure that all individuals with sensory impairments living in RFT areas know what services are available and necessary and have the ability to access them. As advancements in technology continue, additional service options will likely become available and ultimately improve the lives of individuals with sensory impairments in RFT communities.

Resources

American Association of Deaf-Blind: http://wwwaadb.org
American Foundation for the Blind: http://www.afb.org
Center for Hearing and Communication: http://chchearing.org
Gallaudet University
National Association of the Deaf: http://ww.nad.org
National Federation of the Blind: https://nfb.org

Learning Exercises
Self-Check Questions

1. Why is it important for various service delivery entities in rural areas to coordinate services when working with persons with sensory impairment?
2. What is the difference between a hearing loss and deafness?
3. What are some of the social experiences of people with hearing loss in rural areas?

Experiential Exercises

1. Interview an individual with a sensory impairment living in a rural area to identify the challenges they have had to overcome.
2. Work with a rehabilitation counselor to develop a resource manual for persons with sensory impairment living in rural areas.
3. Develop an advocacy plan for a person with a dual sensory impairment living in a rural area.

Multiple Choice Questions

1. Which of the following is not one of the side effects of sensory integration dysfunction?
   (a) Depression
   (b) Cognitive decline
   (c) Motor clumsiness
   (d) Behavioral problems
2. Research suggests that visual impairment is frequently associated with _______ in older adults.
   (a) Heart disease
   (b) Obesity
   (c) Mortality
   (d) Being single
3. Which of the following is not associated with individuals with sensory impairments?
   (a) Lower educational attainment
   (b) Higher poverty
   (c) Poorer health outcomes
   (d) High rates of employment

4. Hearing loss affects roughly how many individuals in the United States?
    (a) 48 million
    (b) 36 million
    (c) 64 million
    (d) 22 million
5. What is considered to be the strongest predictor of hearing loss?
    (a) Income
    (b) Age
    (c) Employment
    (d) Additional disabilities
6. The statutory definition of blindness is a central visual acuity of ______
    (a) 20/400
    (b) 10/200
    (c) 20/10
    (d) 20/200
7. According to research, the majority of individuals with blindness reside in which region of the United States?
    (a) Midwest
    (b) West
    (c) South
    (d) Northeast
8. What is considered to be the number one cause of vision loss?
    (a) Diabetes
    (b) Genetic factors
    (c) Injury
    (d) Age
9. What section of the Americans with Disabilities Act addresses telecommunication?
    (a) Title I
    (b) Title II
    (c) Title III
    (d) Title IV
10. The decreased ability to hear resulting from damage or dysfunction to inner ear structures is known as ____ hearing loss.
    (a) Conductive
    (b) Sensorineural
    (c) Mixed
    (d) Central Auditory Dysfunction

Key

1. B
2. C
3. D
4. A
5. B
6. D
7. C
8. A
9. D
10. B

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Part III

International Vocational Rehabilitation Practice, Employment, and Policy for Rural Development for People with Disabilities

Rehabilitation Practice, Employment, and Policy for Rural Development for People with Disabilities in West Africa

16

Veronica I. Umeasiegbu, Abdoulaye Diallo,
and Bryan O. Gere

Overview
Too often, rehabilitation researchers and professionals may focus on the rehabilitation needs of persons with disabilities in urban areas of the developing world. However, persons with disabilities in rural areas need more attention as this population has more unmet rehabilitation needs. This chapter explores the issues of rehabilitation for individuals with disabilities in rural West Africa. By reading this chapter, you will gain some foundational information on healthcare and rehabilitation needs of persons with disabilities in West Africa, the challenges and barriers that prevent community inclusion, and the implications of these issues to the rehabilitation professionals.

Learning Objectives
Upon completion of this chapter, the reader will be able to:

1. Describe the countries in West Africa.
2. Identify major barriers facing person with disabilities in West Africa.
3. Describe briefly the healthcare delivery system in West Africa.
4. Understand the barriers faced by peopled with disabilities in the West African region.
5. Describe the strategies to increase service delivery to persons with disabilities.
6. Describe the implications for rehabilitation research and practice.

Introduction

The World Health Organization estimates show that about 15% of the world's population is living with at least one form of disability. In addition, 8% of the world's population of people with disabilities live in developing countries. One of the characteristics of developing nations is extensive rural areas with limited educational, health, and other resources. West Africa has vast rural settings. Therefore, most rural villages in West Africa can be regarded as having typical characteristics of such settings with limited availability of resources. Common among the countries of West Africa is that they are classified as developing countries. Chronic poverty is another characteristic of the countries in West Africa. This region has been described as one of the poorest regions of the world, where

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V.I. Umeasiegbu (✉)
School of Rehabilitation Services and Counseling, College of Health Affairs University of Texas Rio Grande Valley, Edinburg, TX, USA
e-mail: veronica.umeasiegbu@utrgv.edu

A. Diallo
School of Rehabilitation Services and Counseling, College of Health Affairs, University of Texas Rio GrandeValley, Edinburg, TX, USA

B.O. Gere
Department of Psychology & Counseling, Alabama A & M University, Huntsville, AL, USA

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most of the residents live on less than $2 dollars per day. Those mostly affected by this chronic poverty are individuals with disabilities and children (Plan International Inc., 2013). Poverty has been shown to have a common relationship with disabilities and vice versa. Poverty results in lack of opportunities to education, healthcare services, adequate source of livelihood, and much more (WHO, 2010).

The authors of this chapter want to emphasize the limited literature on issues of rural health and rehabilitation services for people with disabilities in West Africa. There is acute lack of data on people with disabilities in rural West Africa and limited literature on disability-related issues even in urban settings. Much research is needed in West Africa to understand the impacts of disabilities and service needs of individuals with disabilities in this part of the world. Limited data or lack of data on disability in West Africa is not peculiar to just this region; the World Report on Disability (WHO, 2011) reported limited or lack of disability-related data in many developing countries.

West Africa: An Overview of the Countries

West Africa is a geographic location within the continent of Africa. The population of West Africa is approximately one third of the sub-Saharan African population. West Africa is a vast region with vast population of rural dwellers. The region consists of the following 16 countries: Benin, Burkina Faso, Cape Verde, Cote d'Ivoire, Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Mali, Niger, Nigeria, Senegal, Sierra Leone, Togo, and Mauritania. Before the twentieth century, West Africa suffered abuse and was victim to both slave trade and colonialism. The location of this region of Africa made it a target for invasion by early explorers (Encyclopaedia Britannica, 2016). Table 16.1 is a representation of some vital information on each country of West Africa.

Disability and Service Delivery in West Africa

The concept of disability varies across societies and is central to the status or position afforded by people with disabilities within that society (Eskay, Onu, Igbo, Obiyo & Ugwuanyi, 2012; Mpofu & Harley, 2002). In West Africa, conceptions of disability are largely influenced by long-held religious beliefs, sociocultural beliefs, and traditional practices that define what is considered normal, abnormal, and acceptable (Eskay et al., 2012). Traditional perceptions in West Africa about disability are metaphysical and spiritual in nature. Hence, this society adopts the religious model of disability whereby disability is viewed as the result of influences of a higher power, evil influences, violations of social norms or disobedience to gods, and reincarnation (Avoke, 2002; Rubin & Roessler, 2008). The religious influence on beliefs about disability results in high demand for religious/spiritual form of intervention and treatment. Thus, treatment for many types of disabilities in the informal sector (outside the healthcare system) centers on casting out the evil forces or trying to appease the gods with the aim of obtaining healing for the individual. Disabilities such as psychiatric or intellectual disabilities have high referrals for traditional and religious healers who often perform some form of religious sacrifices, ceremonies, and exorcisms to appease or ward off the evil spirits (Eaton & Agomoh, 2008; Read, Adiibokah, & Nyame, 2009).

Further, traditional treatment for disability also emphasizes the use of herbs, massage, bone setting, body incisions, and other practices for the treatment of physical and mental disabilities (Borokini & Lawal, 2014). The modern view of disability which is based on a blend of medical and functional model of disability (Smart & Smart, 2006) is becoming the norm. Among many healthcare providers in West Africa, individuals with disabilities are considered as sick, lacking ability or the capacity to perform work or engage in social and economic roles within the range considered normal for a human being. Thus, the focus of disability service delivery is to

Table 16.1 Demographic information of countries in West Africa

Country	Country description	Population	% of rural population	Life expectancy at birth	Education and health	Population of PWD
Benin	The Republic of Benin was a French colony from the late nineteenth century until 1960. Benin consisted of several individual kingdoms prior to colonization	10,783,000	56.9%	Male: 60.1 years Female: 62.9 years	Literacy: % total population aged 15 and above, 42.4% Male literacy: 55.2% Female literacy: 30.3% Health: physicians 334 (1 per 23,256 persons); hospital beds 590 (1 per 11,238 persons)	Data not available
Burkina Faso	Burkina Faso was a French colony until 1960 when it gained its independence. The country was previously known as Upper Volta until 1984 when it changed its name to Burkina Faso	18,450,000	70.1%	Male: 52.4 years Female: 56.5 years	Literacy: % total population aged 15 and above, 28.7% Male literacy: 36.7% Female literacy: 21.6% Health: physicians 838 (1 per 20,006 person); hospital beds 6288 (1 per 2500 persons)	Data not available
Cape Verde	A country comprising of a group of islands that lie 385 miles off the west coast of Africa	525,000	34.5%	Male: 68.5 years Female: 73.0 years	Literacy: % total population aged 15 and above, 87.6% Male literacy:92.1% Female literacy: 83.1% Health: physicians 1314 (1 per 385 persons); hospital beds 1076 (1 per 476 persons)	Data not available

(continued)

Table 16.1 (continued)

Country	Country description	Population	% of rural population	Life expectancy at birth	Education and health	Population of PWD
Cote d'Ivoire	This country became a French colony in 1893 and achieved independence in 1960 (Camhaire, Mundt, & Lawler, 2015)	23,327,000	45.8%	Male: 56.9 years; female: 59.2 years	Literacy: % total population aged 15 and above, 43.1% Male literacy: 53.1% Female literacy: 32.5% Health: physicians, 2825 (1 per 7143 persons); hospital beds 10,825 (1 per 1852 persons)	Data not available
Gambia	Gambia is a virtual enclave in the Republic of Senegal. It is one of the smallest countries in Africa	2,023,000	40.4%	Male: 61.8 years Female: 66.5 years	Literacy: % total population aged 15 and above, 55.5% Male literacy: 63.9% Female literacy: 47.6% Health: physicians 156 (1 per 9769 persons); hospital beds 1221 (1 per 1250 person)	Approximately 15% of population
Ghana	Ghana gained independence from Britain in 1957 and was the first sub-Saharan African country to gain independence	27,635,000	46.0%	Male: 63.0 years Female: 67.7 years	Literacy: % total population aged 15 and above, 67.3% Male literacy: 73.2%; Female literacy: 61.2% Health: physicians 2640 (1 per 9124 persons); hospital beds 22,194 (1 per 1111 persons)	Approximately 10% of population

Country	Country description	Population	% of rural population	Life expectancy at birth	Education and health	Population of PWD
Guinea	Guinea was colonized and ruled by France until 1958, when it became independent	10,961,000	62.8%	Male: 57.6 years Female: 60.7 years	Literacy: % total population aged 15 and above, 41.0% Male literacy: 52.0% Female literacy: 30.0% Health: physicians 818 (1 per 12,504 persons); hospital beds 2999 (1 per 3333 persons)	Approximately 15% of population
Guinea-Bissau	Guinea-Bissau was part of the Portuguese Empire for centuries until it gained independence in 1974	1,732,000	50.7%	Male: 47.9 years Female: 51.9 years	Literacy: % total population aged 15 and above, 59.9% Male literacy: 71.8% Female literacy: 48.3% Health: physicians 332 (1 per 5007 persons); hospital beds 16,042 (1 per 104 persons)	Data not available
Liberia	The Republic of Liberia is Africa's oldest republic. The colony was founded in 1816 for the freed American and Caribbean slaves. In 2005, Liberia became the first African country to have a female president	4,200,000	50.3%	Male: 56.0 years Female: 69.0 years	Literacy: % total population aged 15 and above, 47.7% Male literacy: 64.7% Female literacy: 44.0%	Approximately 16% of population

(continued)

Table 16.1 (continued)

Country	Country description	Population	% of rural population	Life expectancy at birth	Education and health	Population of PWD
Mali	Mali is a landlocked country of West Africa. It is one of the largest countries in Africa but with a small population	16,956,000	60.0%	Male: 52.8 years Female: 56.4 years	Literacy: % total population aged 15 and above, 31.1% Male literacy: 43.4% Female literacy: 20.3% Health: physicians 1053 (1 per 10,566); hospital beds 1664 (1 per 6203 persons)	Data not available
Niger	The Republic of Niger is an arid state that is located at the edge of the Sahara desert	18,882,000	81.3%	Male: 53.2 years Female: 55.6 years	Literacy: % total population aged 15 and above, 15.5% Male literacy: 23.3% Female literacy: 8.9% Health: physicians 1029 (1 per 16,673 person); hospital beds 3805 (1 per 3935 persons)	Data not available
Nigeria	Nigeria is the most populous country in Africa. This country was colonized by Britain and got its independence in 1960	181,562,000	52.2%	Male: 51.3 years Female: 53.2 years	Literacy: % total population aged 15 and above, 59.6% Male literacy: 59.6% Female literacy: 49.7% Health: physicians 58,360 (1 per 2698 persons); hospital beds 85,523 (1 per 1609 persons).	Approximately 14% of population
Republic of Senegal	Received independence in 1960 from France. Stable democratic government	14,151,000	56.3%	Male: 58.9 years Female: 63.0 years	Literacy: % of total population aged 15 and over, 57.7% Male literacy: 69.7% Female literacy: 46.6% Health: physicians 253 (1 per 49,975); hospital beds 27,816 (1 per 454 persons)	Approximately 200,00

Country	Country description	Population	% of rural population	Life expectancy at birth	Education and health	Population of PWD
Sierra Leone	Sierra Leone was colonized and ruled by Britain until 1961. The colony was founded by a British organization in 1792 for individuals freed from slavery in America	6,319,000	60.1%	Male: 54.9 years Female: 60.0 years	Literacy: % total population aged 15 and above, 48.1% Male literacy 48.1% Female literacy 37.7% Health: physicians 115 (1 per 50,017 persons); hospital beds 1174 (1 per 5000 persons)	Approximately 450,000
Togo	Togo is a country in West Africa located on a narrow strip of land between Burkina Faso, Benin, and Ghana. It gained its independence in 1960 from France	7,059,000	60.0%	Male: 61.5 years Female: 66.7 years	Literacy: % total population aged 15 and above, 66.5% Male literacy: 78.3% Female literacy: 55.3% Health: physicians 648 (1 per 10,001 persons); hospital beds 4411 (1 per 1429 persons)	Data not available
Mauritania		3,767,000	40.1	Male: 59.7 years Female: 64.2 years	Literacy: % total population aged 15 and above, 58.0% Male literacy: 64.9% Female literacy: 51.2% Health: physicians 445 (1 per 7202 persons); hospital beds 1252 (1 per 2450 persons)	Data not available

Sources: Encyclopaedia Britannica (2016) and World Bank (2016) provide basic medical, educational, and vocational support and vocational support and training that assist persons with disability to achieve some level of functioning and social integration (Obiakor & Afolayan, 2012). All the West African countries lack functional disability-specific service delivery system especially in the areas of education, employment, and transportation and in other vital participation domains even in the urban cities.

Influence of Colonization and Religion on Service Delivery

Formal disability services in West Africa began as part of a rehabilitation program for African soldiers who acquired disability during combat in World War II (Grischow, 2014). This initiative was based on the social model of disability with an attempt to socially and economically reintegrate these individuals into the workforce. At its inception, only soldiers from the former Gold Coast (now Ghana) were targeted for vocational rehabilitation and placement in urban labor markets or sheltered workshops. Soldiers with temporary or partial disabilities were taught trades in occupations that they could pursue individually or in a sheltered workshop or in government employment, whereas soldiers with permanent disabilities were placed in long-term care or asked to return to their families. By mid-1945, soldiers from other West African countries such as Nigeria, the Gambia, and Sierra Leone, including civilians, were included in the program. However, the program lost its momentum and was abandoned by the colonial government in 1947 (Grischow, 2014). During the late 1950s and early 1960s, the then president of Ghana, Kwame Nkrumah, revived this vocational rehabilitation program and achieved much success that led to extension of the program to the rural areas of the country. The focus of this early rehabilitation program was on basic skills training in the areas of carpentry, metalworking, and farm gardening (Ghana Department of Social Welfare and Community Development [GDSWCD], 1966).

Between the years 1945 and 1970, church missions were the mainspring behind the establishment and maintenance of disability and social programs for children and adults with disabilities in Nigeria (Garuba, 2003). The missionaries were the first to introduce schools for the deaf and the blind across the country (Obiakor & Offor, 2011). Following the Nigerian Civil War (1967–1969) which resulted in a higher incidence rate of disabilities, the federal government of Nigeria increased their attention toward issues of disability. For instance, as an initial effort, the government took over the missionary schools and released a national policy on education emphasizing the need of special education (Garuba, 2003). Over time, the government increased the number of schools, community-based vocational rehabilitation centers, and workshops, for individuals with physical, visual, and hearing disabilities, with a view to assisting them secure sustainable long-term employment (Obiakor & Offor, 2011; Renne, 2013). Currently, colonization has a significant influence in the pattern, availability, and delivery of disability services in West Africa (Obiakor & Afolayan, 2012). For instance, a significant part of the service delivery framework used in both the public sector and private rehabilitation institutions is based on the model used by the missionaries in their vocational centers and mission schools.

Impacts of Nongovernmental Organizations (NGOs) on Service Delivery

There is gross lack of affordable and appropriate disability services for individuals at the state and local levels in Nigeria as well as in the other countries of West Africa (Lang & Upah, 2008). The few disability-related organizations and services for people with disabilities are located in the urban cities. The bulk of disability and rehabilitation services are typically provided by private institutions such as religious organizations and nongovernmental agencies (NGOs). NGOs provide direct support services to people with disabilities to enhance their ability to achieve economic self-sufficiency and community inclusion. NGOs work with organizations of people with disabilities to facilitate advocacy and human rights activities (Lang & Upah, 2008). In Guinea, Ghana, Sierra Leone, and Liberia, Christian Blind Mission International (CBM) supports work related to disability, including medical services, education, and rehabilitation for people with disabilities (mainly for people with visual disabilities, hearing disabilities, physical disabilities, mental disabilities, or intellectual disabilities) (UNHCR, 2008). During the recent Ebola virus outbreak in some parts of West Africa, missionary groups from various organizations, including Samaritan's Purse and Catholic Relief Services, worked alongside doctors, nurses, and relief workers to eradicate Ebola crisis in Liberia, Guinea, and Sierra Leone (Dianna, 2014). Handicap International helped prevent Ebola by ensuring Sierra Leone citizens are informed and educated about Ebola (Handicapped International, 2016).

Some charitable organizations have also played crucial roles in championing the causes of disabilities, especially for certain types of disabilities (e.g., severe visual impairments). For example, in Sierra Leone, the UK Association for the Blind supports the Milton Margai School for the Blind (Open Charity, 2010; The UK Association for the Blind in Sierra Leone, 2010). In Guinea, Disabled Peoples' International (DPI) has promoted human rights of persons with disabilities through full participation and equalization of opportunity and development (UNHCR, 2008). In Ghana, Action on Disability and Development-Ghana empowers women with disabilities to take part in the decision-making process within both the disability movement and the mainstream women's movement in order to explore and solve issues pertinent to women. Also, the Italian Association Amici di Raoul Follereau (AIFO) supports persons with disabilities and the poor and vulnerable group through community-based rehabilitation (Naami & Hayashi; UNHCR, 2008). For example, in Liberia and Senegal, Handicap International through their efforts in preventing disability and disease, community health services, and provision of psychological support for individuals with disabilities (Handicap International, 2015).

The services provided to people with disabilities in West Africa are desirable as well as commendable; unfortunately, the predominant disability model used in service delivery in some of these NGOs is the tragedy or charity model which espouses that individuals with disabilities are victims of circumstances that:

1. Deserve pity and compassion
2. Incapable of taking care of themselves or managing their own affairs
3. Should be supported with charitable donations to meet their economic and social obligations (Nikora, Karapu, Hickey, & Te Awekotuku, 2004)

Government and Government Policies

Government support in terms of funding and provision of a sociopolitical policy framework that addresses disability issues is very minimal in countries in West Africa (Lang & Upah, 2008; Tinney, Chiodo, Haig & Wiredu, 2007). Medical rehabilitation facilities are scarce and in a parlous state (Eaton & Agomoh, 2008; Tinney et al., 2007), and vocational rehabilitation facilities and special education programs are poorly funded and under-managed (Obiakor & Offor, 2011). Additionally, in both Nigeria and Ghana, the Ministry of Social Welfare, not the Ministry of Health, is a primary government agency responsible for disability issues. Within this framework, the government's approach to disability service provision is guided by the underlying ideological belief that disability issues should be addressed through charity and welfare (Lang &Upah, 2008; Tinney et al., 2007). In 1993, the Nigerians with Disability Decree (1993) was promulgated, but no policies were formulated to enable its implementation.

All the countries in West Africa have either signed or ratified the UN Convention on the Rights of Persons with Disabilities (including the optional protocol) (United Nations, 2016).

Before the existence of the Convention, there is no disability legislation that provides a framework for the delivery of disability services and prohibition of discrimination and ensures equal rights and access to opportunities for persons with disability (Akhidenor, 2007; Eaton & Agomoh, 2006). While many West African countries are in some respect in line with the UN Convention on the Rights of Persons with Disabilities, yet the impacts of the Convention is yet to be noticed in West Africa. Most developmental efforts in this region have been in urban areas, with little, if any, attention to rural areas, where health, both physical and mental, and educational resources for persons with disabilities are unavailable (Children in Crisis, 2013). Yet, the percent of the rural population compared to the urban residents of West African countries is very high (see Table 16.1 for percent for rural population), and resources are barely available in rural areas (World Bank, 2016). Presently, there is no disability infrastructure or support system in public institutions including schools, recreation facilities, and places of work; thus, persons with disability are not well integrated into the society. This is especially the case for the vast majority of Nigerians with disabilities, especially those living in rural areas (Lang & Upah, 2008).

The Ghanaian government legislated disability policy includes the 1992 Constitution, the Persons with Disability Act of 2006, and the Mental Health Act of 2012 (Doku, Wusu-Takyi, & Awakame, 2012). Similar to other West African countries, implementation of these policies has been largely hampered by political, organizational, and structural problems, as well as sociocultural beliefs. Tijm et al. (2011) emphasizes that the realization of disability policy in Ghana will depend on the changes in both the physical and social environments. In Sierra Leone, the government has supported the Milton Margai School for the Blind that was founded in 1956 by Wilhemina Johnson, who had a certificate in special education from the United Kingdom and who herself had visual impairment (Open Charity, 2010; UK Association for the Blind in Sierra Leone, 2010). The 1991 Constitution of Sierra Leone provides protection for the rights of persons with disabilities in such areas as welfare and educational opportunities. The countries of West Africa need to commit to a system-wide implementation of disability legislations including building of accessible public infrastructure to increase the community participation and inclusion of persons with disabilities. It is worth noting that the UN, in its efforts to champion the right and protection of persons with disabilities, has positively influence West African policies related to person with disabilities. The UN Convention on the Right of Persons with Disabilities has set the stage for countries to change discriminatory practices against persons with disabilities (Disabled World, 2016).

Employment and People with Disabilities in West Africa

Persons with disabilities in rural West African areas are hardworking citizens of their various countries. Many of these individuals are not literate due to lack of opportunities and inaccessible educational environment and programs. Despite multifaceted barriers encountered daily by these individuals with disabilities in the rural villages, some of these individuals strive to survive and even contribute to the economy of their communities. These individuals can be seen working in farms, engaging in various productive activities including cobbling, begging for livelihood in the market places, weaving mats, and engaging in other activities in order to provide daily food for themselves and their families. It is noteworthy to emphasize here that the living situations and daily barriers in these rural villages hinder self-actualization, well-being, and quality of life of persons with disabilities in rural West Africa.

The major parts of these barriers are lack of assistive technology such as wheelchairs for community participation of these individuals and limited availability and in most cases none existence of rehabilitation programs to assist with education of children with disabilities. For example, a Sierra Leone study shows that children with disabilities are much less likely to attend school than children without disabilities. The chances of attending school become even slimmer if that person is a girl with a disability (World Bank, 2009). Without proper skill training and education, people with disabilities in rural West Africa do not have any chance of securing meaningful employment, getting out of poverty, and enjoyment of a better quality of life. Issues related to employment of persons with disabilities in rural areas of West Africa can be managed using the concepts and principles of community-based rehabilitation (CBR). (See section on CBR for more detailed discussion of the CBR concepts.)

Barriers to Service Delivery for People with Disabilities in West Africa

Access to healthcare services is indispensable in meeting health-related human right (World Health Organization, 2008). Despite the obvious importance of health as a right, many citizens of the world, especially those in the developing countries, do not have access to healthcare services. The World Health Organization's (WHO, 2010) report emphasized the healthcare services and health workforce crisis in most of the sub-Saharan Africa. All the countries in West Africa fall under the developing country category; hence, the healthcare system in most of these countries is still developing and is understudied. West African countries face healthcare and service-related crisis due to many factors such as the ones discussed in this chapter. The healthcare and service-related crisis are most pronounced in rural and remote areas or villages. For instance, Awofeso (2010) reported that about 52% of the Nigeria population live in rural villages with limited and in most cases absent of healthcare infrastructures. Many barriers to services to individuals with disabilities exist in all West African countries. Some of these barriers are highlighted as follows:

Belief System and Attitude Toward Disability

Belief system influences attitude of any individual. The beliefs of someone on an issue can result either in positive or negative attitudes toward that same issue. The beliefs of rural West African villagers about disability are influence by prevailing philosophies on the meaning of disability. According to Umeasiegbu, Mpofu, and Johnson (2012), religious and cultural beliefs are important factors toward access to community resources to individuals with disabilities. Traditional values and practices, rituals, norms, and expectations are some of the factors that "pose barriers to community participation" (p. 107) to different areas of village life for persons with disabilities. In most countries in West Africa, there are superstitious beliefs about disability. The superstitious beliefs include that disability is act of God (e.g., punishment for sin committed) or the result of witchcraft or evil spirit or unfinished issue from past life (for some traditional West African religion who believe in reincarnation). "Many such cultural and religious beliefs are associated with stigma and shame for people with disabilities and their families. Culture and religious beliefs can perpetuate myths, stereotypes, and other negative attitudes of the society" (Umeasiegbu et al., 2012, p. 107). Belief and perceptions about disability in West Africa are much diversified, a mixture of positive and negative perceptions and beliefs. According to Wright (1960), some villages in Benin regard children born with disabilities as protected by supernatural power, while in some tribes in Nigeria, reactions to childhood disabilities vary from overprotection to total rejection. Among the Ashanti tribe of central Ghana, it is traditional to preclude men with physical disabilities from performing community leadership such as becoming chiefs. Disability, such as epilepsy, is enough ground to destool a chief from office (Sarpong, 1974). Moreover, some Christian churches in Nigeria still regard PWDs in need of prayer in order to be delivered from evil spirits, which is believed to have caused the disability. Such beliefs are barriers to seeking medical care and rehabilitation. Munyi (2012) stated that the "desire to avoid whatever is associated with disability has affected people's attitudes towards people with disabilities simply because disability is associated with evil. Most of these negative attitudes are mere misconceptions that stem from lack of proper understanding of disabilities and how they affect functioning" (p. 3).

Lack of Policy Implementation

Many countries in Africa have adopted policies and legislation aiming at the promotion of human rights for people with disabilities. These West African countries have disability-related legislations on “paper,” but the implementation of such disability legislation is lacking in most of these countries. Some countries within the region such as Sierra Leone have a developing disability legislation. Countries in West Africa have neglected the human rights of individuals with disabilities. Umeasiegbu, Bishop, and Mpofu (2013) stated that “the mere existence of formal recognitions in constitutions…do not necessarily lead or equate to implementation; the rights of persons with disabilities have consistently and continually been inadequately recognized or protected” (UN, 2010). Obviously, the rights of person with disabilities in the West African region have been denied leading to abuse, discrimination, lack of access to built and natural environment, and exclusion from educational and economic participation. One of the reasons for non-implementation of disability-related legislation in this region is the lack of “godfathers” for people with disabilities within the political system of these countries. The governments of these countries are not interested in the welfare of individuals with disability. Unfortunately, this population does not have “voice” nor political power within the government of their respective countries.

Change is gradually coming to this African region. Currently, most countries in West Africa have ratified the United Nations’ Convention on the Rights of Persons with Disabilities (CRPD). The signing and ratification of this international convention by these developing countries are applauded. Signatory and ratification of international disability convention should not be the end of the action by these countries. The CRPD is an international convention adopted by the United Nations’ General Assembly on December 13, 2006. The goal of the CRPD is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (United Nations, 2006, Article 1., para. 1). The essential principles of the CPRD include (a) respect for inherent and individual autonomy, (a) nondiscrimination, (c) full participation and inclusion in the society, (d) equality of opportunity and accessibility, (e) equality between men and women, and (f) respect for the evolving capacities of children with disabilities and respect for the rights of children with disabilities to preserve their identity (Umeasiegbu et al., 2012; UN, 2006; WHO, 2010).

Chronic Poverty

Chronic poverty is endemic in West Africa. For example, Sierra Leone is regarded as one of the poorest countries in the world despite that the country is rich in natural resources. Disability and poverty are said to go together as both conditions have direct impacts on each other (World Bank, 2009). The presence of a disability in a family compounds poverty status of the family. Disability is generally expensive, and hence, the little resources of the family are spent on food rather than on the needs of the family member with the disability. Social support from the government is mostly absent in countries in West Africa; therefore, the burden for caring for the person with a disability is solely on the family. Most people with disabilities and their families are the poorest of the poor. It is common to see individuals with different types of disabilities on the streets of urban cities begging for money. Many individuals with disabilities do not have access to assistive technology such as wheelchairs, braille materials, and others. The lack of resources to acquire assistive technology and obtain education and other necessities of life prevents general community participation of people with disabilities. Poverty among women and girls with disabilities is worse than among men with disabilities. For example, in Eastern Nigeria, it is traditional for male children to receive inheritance from their fathers. Female children are denied such inheritance. Therefore, women and girls with disabilities are disempowered by this tradition (Umeasiegbu & Harley, 2014).

Strategic Approaches to Enhancing Service Delivery for People with Disabilities

Enhancing service delivery for the rural populations of people with disabilities in West Africa is not impossible, but to achieve these, coordinated efforts by the various country governments are required. This section discusses some of the strategies that may improve the provision of services for individuals with disabilities residing in rural communities. The strategies to accomplish this goal include (a) implementation of country and international disability-related laws, policies, and legislation, (b) awareness creation about disability, (c) establishment of funds to mainstream disability issues into the society, (d) advocacy efforts, and (e) increase resources and infrastructures.

Legislative Implementation and Monitoring

A major barrier to service delivery to individuals with disabilities in West Africa is the lack of implementation of existing legislations and, worse still, the nonexistence of such disability legislations. Any law or legislation is devoid of its power without the implementation of such law. Countries in the West African region need effective implementation of existing disability laws, amendment of laws that are lacking essential components, and enactment of laws where there are no such laws. The governments of various countries in this region need to be held accountable for implementation of legislations. The signatory and ratification of the CRPD by the countries in West Africa are progressing toward human rights recognition of people with disabilities and future improvement in service delivery both to persons with disabilities in the rural, suburban, and urban areas. Effective policy implementation may not happen overnight, but with advocacy, these countries will progress toward societal inclusion of people with disabilities.

The UN's CRPD requires that monitoring of the implementation violation of the CRPD be carried out for each UN member state who ratified the convention. The monitoring is undertaken through reports from the UN member states, organizations of people with disabilities, human right organizations, the UN, and other organizations (UN, 2010). The CRPD implementation and monitoring are still emerging issues which will fully develop overtime. Currently, the criteria for evaluating or assessing a country's implementation are not well understood in terms of the evaluation for developed and developing countries. It is obvious that many developed countries have robust disability legislations and implementation of such legislations and, therefore, different levels of evaluation may be necessary. The story is not the same for many of the West African countries who have very little or nothing in terms of established disability legislation implementation.

Strategic Plan for Action. A vital step toward implementation of disability-related local and international policies is the setting of national agenda by individual West African countries. Umeasiegbu and Harley (2014, p. 127) recommended that for effective societal inclusion of people with disabilities, each country's government needs "to identify strategies for implementation and monitoring of the …CRPD by incorporating it into their developmental efforts at all levels of organizational structure, policy formation, economic priority, cultural and community pursuits, and educational opportunities."

Awareness Creation on Disability

There are many traditionally held beliefs, values, and customs that are detrimental to individuals with disabilities and disability-related development in the West African region. Sometimes myths and stereotypical beliefs about disability are maintained as culture. Some of these cultural practices in fact cause disabilities. For instance, some tribes in Nigeria practice female genital cutting, otherwise known as female circumcision. Female circumcision may lead to sexual-related dysfunctions and psychological problems in women and girls.

Disability awareness is needed both in urban and rural areas. There is need for awareness about the causes of disability, such as that disability may result from medical condition and diseases, wars, accidents, and others. Awareness should also focus on how social conditions or situations can worsen or improve the situation of people with disabilities. The country governments, community leaders/elders, religious leaders, healthcare professionals, teachers, nongovernmental organization, and organizations of people with disabilities need to be involved in this awareness creation campaign. Children with disabilities especially girls in rural areas of West Africa are less likely to go to school as the results of their disabilities and shame by family members. Many families with children with disabilities feel ashamed about the disability status of the family members. One of the ways these families deal with this shame is to hide that family member from the public, including exclusion from participation in school, church, and family social occasions. Creating awareness about the need to seek medical help, school attendance, and employment are crucial to independence and community participation of individuals with disabilities. According to the WHO (2010), awareness raising enables people to recognize opportunities for change. "Raising awareness in families and communities about disability issues and human rights can also help to remove barriers for people with disabilities so they have greater freedom for participation and decision-making" (Empowerment component, p. 4).

Advocacy for Social Justice in Service Delivery

Social injustice against persons with disabilities is common in all the countries of West Africa. Injustice is seen in every facet of life and unfortunately even considered the norm. In order to tackle the multi-faced problems confronting persons with disabilities, access to social justice becomes paramount. Advocacy and social justice systems that redress the injustices and address needs of people with disabilities are urgently needed. People with disabilities need representations in all the ministries (justice, health, education, social affairs, finance, transportation, and others) of their country's government.

The CRPD is an instrument for national and international advocacy and provides background information and instructions on various areas of needs that can be the focus of advocacy efforts. Each country will need the formation of disability advisory council which will focus on immediate issues of injustices and how to remedy unfair situations. The civil society groups and organizations of people with disabilities should be represented on the country's disability advisory council. Local and international NGOs have tremendous roles to play in advancing social justice and service delivery for people with disabilities in West Africa.

Community-Based Rehabilitation

The use of community-based rehabilitation (CBR) as a form of service delivery for PWDs is of particular importance for individuals residing in rural areas within West Africa. CBR is an innovative concept first initiated by the WHO (2010) as a follow-up to the 1978 International Conference on Primary Health Care and the Declaration of Alma-Ata. The Alma-Ata Declaration was the first international advocacy effort on primary healthcare (the *health for all* strategy) by the WHO. CBR involves collaborative efforts from the WHO, United Nations (UN), nongovernmental organizations, and local institutes of PWDs. Initially the CBR "was primarily a service delivery method making optimum use of primary health care and community resources and was aimed at bringing primary health care and rehabilitation services closer to people with disabilities, especially in low-income countries" (WHO, 2010, p. 23).

In recent years, CBR model of service delivery for PWDs has expanded into five interactive and complex components (known as CBR matrix) which includes health, education, livelihood, social, and empowerment. A highly recommended read on CBR is the WHO's (2010) publication entitled *Community-based Rehabilitation: CBR Guidelines.* The WHO's CBR Guidelines emphasize.

Education for People with Disabilities

Education is an important agency for individual and national development. Education is a force for self-reliance, poverty reduction, promotion of quality of life, and sustainable development (Umeasiegbu & Harley, 2014; UNICEF, 2016).

According to Umeasiegbu and Harley (2014, p. 119), "education empowers" people "with disabilities to get involved in their health care needs, be self-advocates, and participate in community development."

International Collaboration Recommendations

Africa is one of the parts of the world that remains grossly unexplored in terms of disability and rehabilitation-related research, practices, and education. West Africa provides unique opportunities for exploration and applications of rehabilitation counseling research, education, and practice. The authors of this chapter see the expansion of rehabilitation counseling profession through global collaboration in West Africa. Discussed in this section are ideas for international collaboration in West African countries. Suggested ideas for collaboration include collaborative advocacy efforts, research, education, and rehabilitation practice exchange program.

Collaborative Advocacy Efforts

One of the important events of the twenty-first century for the disability community is the institution of the Convention on the Rights of Persons with Disabilities (CRPD) by the United Nations (2006). The purpose of the CRPD is to promote and protect the rights of individuals with disabilities and to increase their participation in the society. The CRPD presents the opportunities for rehabilitation counseling profession to be involved in the fostering of global inclusion of people with disabilities. There is need for new objectives toward the development of global rehabilitation intervention that will increase advocacy and social justice for people with disabilities.

The rehabilitation profession can play unique roles in advancing global social justice, equity, and advocacy for persons with disabilities. International advocacy can be achieved in numerous ways including involvement in international organizations such as the WHO, UN, International Labour Organization (ILO), Rehabilitation International, World Bank, and others. These international organizations are involved in global collaborative development efforts with countries, including countries in West Africa. For instance, graduate students in rehabilitation counseling can seek internship opportunities with these international organizations. Internship with such international organizations will provide opportunity to learn about global disability policies and rehabilitation needs of individuals with disabilities in the West African region and hence may increase interest in international advocacy work. Such interns may be assigned by the international organization to work with a country's government on issues of human rights, policy development and implementation, education of children with disabilities, access to healthcare services, employment, or other capacity development efforts.

Collaboration in Research

In 2014, the WHO (2014) released a new document entitled *WHO Global Disability Action Plan 2014–2021: Better Health for all People with Disability.* The WHO action plan includes three objectives: "(1) to remove barriers and improve access to health services and programs; (2) to strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation; and (3) to strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services" (p. 5). The rehabilitation professional has relevant obligation to assist in the fulfillment of these global objectives. Rehabilitation counselor educators especially are dedicated to research that improves the quality of life of persons with disabilities; hence, the WHO action plan creates opportunities for international research by rehabilitation professionals.

Opportunities for original research abound in West Africa especially in the rural villages with a large population of individuals with different types of disabilities. Many dimensions of disability remain unexplored; hence, West Africa is an excellent "laboratory" for disability-related research. Researchers interested in conducting research in West Africa will need to develop partnerships with researchers of African descent and various NGOs and organizations of persons with disabilities who are already doing advocacy and developmental work in those areas and, therefore, have knowledge of the areas. A major challenge for international research is obtaining the needed funding from grant awarding agencies. Funders may have priority areas and interests that may differ from the researchers' interests. Nonetheless, sources for international research may include organizations such as the government of the African country, Fogarty International Center, American Association of University Women, American Psychological Association (international funding and awards), Fulbright Program, Baxter International Foundation, US Department for International Development (USAID), Department for International Development (DFID), and others.

Capacity Building in Rehabilitation

One of the ways to strengthen and improve service delivery in rural West African communities is through capacity building. Capacity building is defined by the WHO (2016, para. 3) as "the development and strengthening of human and institutional resources." Both human and institutional resources are lacking in both urban and rural West African areas. There is acute shortage of healthcare service providers. The available service providers are concentrated in urban areas where hospitals and clinics are mostly located. The few clinics in the rural areas are not adequately equipped for even minimal service provision.

At national levels, many of these countries are poor and do not have the resources and support services to provide assistance for their citizens with disabilities. Developed countries "rely on clinically trained professionals for service delivery in a structured setting, but in developing countries, rehabilitation is mostly by families in unstructured settings" (Umeasiegbu et al., 2013, p. 108., as cited in Mpofu & Harley, 2002). The shortage of healthcare providers in most countries of the developing world is a limitation to service delivery to persons with disabilities. Moreover, most healthcare providers in West Africa practice their profession based on medical model of disability as opposed to social model. Many healthcare providers are not trained in the areas of psychosocial impacts of disability and may not even be familiar with rehabilitation needs of persons with disabilities.

Rehabilitation counselors are knowledgeable on psychosocial implications of disability and hence in a better position to provide international capacity building (training, education, and consultations) to healthcare providers, NGOs, government officials, and persons with disabilities and their families. Bentley, LeBlanc, Bruyère, and MacLachlan (2016) described an international capacity building initiative between Johns Hopkins International Injury Research Unit and Makerere University in Uganda, East Africa, thus:

> The project aims to strengthen trauma, injury, and disability research and educational capacity in Uganda. Aims of the project are to develop a core group of researchers at Makerere University, promote research around key national priorities, establish a national forum, and create a research locus/program…The expected outcome will be a sustainable research enterprise that is for Ugandans by Ugandans with the technical assistance of Johns Hopkins as a partner institution (p. 72).

Rehabilitation Exchange Programs

The partnership between Johns Hopkins International Injury Research Unit and Makerere University, Uganda, is also an example of some form of exchange program in some ways. Exchange programs provide opportunities for rehabilitation professionals, educators, researchers, and students to visit developing countries such as countries in West Africa to provide services such as direct counseling and interventions, research, education and training, and engagement in policy development and implementation. Rehabilitation educators can participate in exchange program using their sabbatical or other research opportunities.

Summary

Individuals with disabilities in West Africa face multiple challenges due to multiple problems such as lack of implementation of disability-related legislations, poverty, and absence of resources. These challenges are made worse by residing in rural areas of West Africa. These challenges can be ameliorated by strategic plans by the countries of the region and their international allies such as rehabilitation professionals.

Resources

The following websites provide additional information or resources:

1. World Health Organization's Regional Office for Africa: http://www.afro.who.int/index.php
2. United Nations Office for West Africa: http://unowa.unmissions.org/
3. United Nations Convention on the Rights of Persons with Disabilities: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html
4. World Health Organization's World Report on Disability: http://www.who.int/disabilities/world_report/2011/report/en/
5. World Health Organization's community-based rehabilitation (CBR): http://www.who.int/disabilities/cbr/en/
6. World Bank Disability and Development: http://www.worldbank.org/en/topic/disability/overview

Learning Exercises

1. Identify one nongovernmental organization (NGO) in West Africa, and learn about its work. Compare this NGO with a nonprofit organization in your community. What are the similarities and differences between these organizations?
2. The world is now a "global village" due to increased technology such as the Internet. Watch or listen to international news through organizations such as CNN International and BBC. What have you learnt about our world? In what ways can you make a difference in the lives of the world citizens who have disabilities?
3. Read about the United Nations Convention on the Rights of Persons with Disabilities (CRPD): https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html. What has your country done about the CRPD? How can you apply the principles of the CRPD in your research and practice?

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The Asia and Pacific Region: Rural-Urban Impact on Disability

17

Daniel W. Wong and Lucy Wong Hernandez

Overview
This chapter will provide a view into the Asia and Pacific regional systems, policy changes, and socioeconomic development programs that are initiated to address disability issue as they relate to prevention, rehabilitation, and maintenance in the region. The following objectives are specific to discuss the demographical, social, political, and economical changes of this region and how these changes impact the quality of life in individuals with disabilities. Further, this chapter will also present the contributions from various entities from the United Nations, international organizations, national governments, and non-government organizations, including grassroots organizations with respect to working with persons with disabilities.

Learning Objectives

1. Define the Asia and Pacific region.
2. Understand the socioeconomic and cultural implications of the Asia and Pacific region.
3. Identify the demographical, social, political, and economical changes of the region and its implications to the populations of persons with disabilities.
4. Examine the ongoing efforts of community-based rehabilitation and disability-related policies, programs, and services.
5. Review national and international works and contributions.

Introduction: Overview of the Asia and Pacific Region

The Asia and the Pacific region is home to over 4.4 billion people or 60% of the global population, accounts for over 40% of the global economy, and is home to nearly 70% of the world's poor and most vulnerable populations including people with disabilities who are scattered throughout rural areas or crowded into towns and cities on a land area of almost 45 million km^2, roughly 17% of the world's surface. The region has a highly varied range of climatic and agro-ecological zones with large areas that have been affected by climate, natural disasters, and social degradation over the past 50 years including drier areas that are particularly vulnerable, and 39% of the region's population lives in areas prone to drought and desertification.

The Asia and Pacific region is divided into five subregional areas: East and Northeast Asia, North and Central Asia, Pacific, South and Southwest Asia, and Southeast Asia. It is a multicultural diverse region with seven of the world's ten most populous countries and also

D.W. Wong (✉) • L.W. Hernandez
Department of Counseling, Educational Psychology and Foundations, College of Education, Mississippi State University, Starkville, MS, USA
e-mail: dwong@colled.msstate.edu

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some of the world's smallest island nations and territories in the Pacific. Geographically, it ranges from fragile Small Island Developing States in the Pacific to populous and vast plains of South and Southeast Asia, as well as the mountainous, landlocked countries of Central Asia (UN-ESCAP, 2015).

Poverty in Asia is a massive problem affecting all populations. Reducing poverty for large numbers of poor people was considered crucial to achieving the primary UN Millennium Development Goal of reducing poverty. Disability issues have increasingly become important factors in poverty reduction efforts, as there is a higher rate of disability among the poor. It is also noticeable that poverty reduction programs have become the major approach to resolve issues of persons with disabilities in rural areas as a high percentage of disabled persons in the rural area are among the poorest of the poor. More than two thirds of the world's poor people live in Asia, and nearly half of them are in Southern Asia. The same situation is evident among the population in the Pacific island nations. Poverty is basically a rural problem in Asia: in the major countries, 80–90% of poor people live in underdeveloped isolated rural areas. While Eastern Asia and Southeastern Asia have made impressive progress in reducing rural poverty over the past three decades, progress has been limited in Southern Asia. Natural disasters such as tsunamis and earthquakes that have struck the region will be taking a toll for years to come in Indonesia, Maldives, Sri Lanka, and Thailand among other regional and coastal areas.

Despite wide-ranging diversities in the region, many poor rural people in Asia share a number of economic, demographic, and social characteristics, the most common of which is landlessness or limited access to land. Poor rural households tend to have larger families, less education, and higher underemployment and unemployed. They also lack basic conveniences such as safe water supply, sanitation, and electricity. Their access to financial credit, equipment, and technology is severely limited. Other constraints, including the lack of market information, business and negotiating experience, and collective organizations, deprive them of the power to compete on equal terms in the marketplace. All of these factors severely affect quality of life of the regional population including people with disabilities.

In 2010, approximately 43% of the Asia and the Pacific population lived in urban areas, the second lowest urban proportion of a region in the world; however, in the last two decades, the Asia-Pacific urban proportion has risen by 29%, more than any other region. Between 2005 and 2010, the urbanized proportion of the world's population overtook the rural population (rising from 49% in 2005 to 51% in 2010); and the urban population continues to grow (the average annual growth between 2005 and 2010 was 1.9%) mostly of poor and close to poverty-level populations. As of 2010, Asia and the Pacific is the second least urbanized region of the world, with only 43% of the population living in urban areas; however, it has the second fastest urban population growth rate, at an average of 2.0% per year (2005–2010). Across the Asia-Pacific region, the urban proportion and urban population growth rates vary dramatically (UN World Population, 2015). The rural economy has become increasingly linked to a rapidly integrating world economy, and the rural society in Asia and the Pacific region faces new opportunities and challenges. The transformation of rural Asia and Pacific has been also combined by some troubling development and that is the significant gap between the rich and the poor. While large part of the region has prospered, Asia and most of the Pacific region remains home to the majority of the world's poor. Growing inequalities and rising expectations in many parts of rural Asia and the Pacific have increased the urgency of tackling the problems of rural extreme poverty. The rapid exploitation of natural resources is threatening the sustainability of the drive for higher productivity and incomes in some rural areas and in general is affecting the entire region.

The regional growing population and booming economies, in some area, exert considerable strain on the region's society and economic and environmental resources. Similar to other world regions with developing nations and vast diverse populations, not enough has been done to equalize opportunities for those who want to contribute to their communities and want to participate in a growing society. As expected the most vulnerable groups (women, children, persons with disabilities, and the aging populations), in particular those living in rural and isolated areas, are at the bottom of the socioeconomic scales and continue to have multiple barriers to access and participation in all facets of society.

In countries undergoing a rapid transition from underdeveloped to developing and moving toward industrialized modernization such as the case of the People's Republic of China (PRC), we can still see evidence of poverty and disability. It is estimated that in China there were about 20 million impoverished disabled people in 1992. Among the disabled poor in rural areas, 30% lived in state-designated impoverished counties. One third of the total poor populations are persons with disabilities in China (ILO, 2002). Over the past two decades, a series of positive legislative and administrative action has been developed for the purpose of improving the living conditions and social status of people with disabilities in the country. The Constitution (enacted in 1982 and amended in 1988, 1993, 1999, and 2004) provides a general principle on the protection of people with disabilities. The Law on the Protection of Disabled Persons (enacted in 1991 and amended in 2008) is of significant importance to safeguard the rights of people with disabilities. It addresses issues of rehabilitation, education, employment, cultural life, welfare, access, and legal liability, among other social issues. The amendment added details about stable financial support, disability pensions, accessible medical care, and rehabilitation services for persons with disability, along with favorable job opportunities and tax policies.

The China Employment Regulation and the Education Regulation for people with disabilities were adopted in 1994 and reinforced by amendments in 2007, respectively, to promote equality, participation, and social inclusion, as well as to prohibit discrimination based on disability.

In addition, more than 50 PRC national laws contain specific provisions concerning people with disabilities, including the new Law on Employment Promotion. China is also advocating and supporting international standards to protect and promote the rights of people with disabilities in a comprehensive manner. The Chinese government has ratified the ILO Convention No. 159 on Vocational Training and Employment (of Disabled Persons) drafted in 1988 and the UN Convention on the Rights of People with Disabilities in 2008, to enable people with disabilities to secure, retain, and advance in suitable employment and to further enjoy integration or reintegration into society.

The organization and work of local nongovernmental organizations such as organizations of parents of children with disabilities at the local community level are more evident now than ever as they work in collaboration with the local entities responsible for disability-related work and other international partners such as WHO and ILO and academic institutions from different Western countries. The most recognizable government-based organization in China is the China Disabled Persons' Federation (CDPF). The CDPF was established in 1988, and it is a unified organization of and for the 83 million persons with various categories of disabilities in China. It has a nationwide umbrella network reaching every part of China with about 90,000 full-time workers and over 400,000 part-time workers who provide services, support, and advocate for persons with disabilities.

The CDPF performs three functions: (1) represent interests of people with disabilities in China and help protect their legitimate rights, (2) provide comprehensive and effective services to disabled people, and (3) commissioned by the Chinese government to supervise affairs relating to people with disabilities in China. The CDPF is committed to improving the lives of people with disabilities, protect the human rights of people with disabilities, and promote the integration of people with disabilities in all aspects of society in China. Much progress is being observed on these efforts and more is expected in years to come (CDPF, 2015).

International Partner Efforts in the Region

Among international partners working in the Asia and Pacific region is the United Nations Environment Programme (UNEP) organization which was established in 1972 to guide and coordinate environmental activities within the United Nations (UN) system for the region. UNEP promotes international cooperation on environmental issues, provides guidance to UN organizations in the field, and, through its advisory groups, encourages the international scientific community to participate in formulating policy for many of the UN's environmental projects spread throughout the region. The UNEP Headquarters is located in the African region in Nairobi, Kenya, from which all world region offices are reached and organize participation by the private sector to promote the sustainable use of the world's natural resources that will benefit the society. UNEP has been one of the UN system organizations that conduct significant work in the region, and it operates through its Regional Office for Asia and the Pacific based in Bangkok, Thailand, working in 41 countries in the region. UNEP works with governments, local authorities, civil society, other UN entities, regional and international institutions, as well as grassroots organizations and the private sector to develop and implement operational policies and strategies that transform efficient use of the region's natural assets and reduce degradation of the environment, communities, and risks to both populations and the socioeconomic development of the region. Despite expanding economies and an accelerated pace of change across the Asia and Pacific region, more than 700 million people continue living in multidimensional poverty in the region. Most recently, surge in urbanization has seen the region's slum population top more than 250 million people, where significant numbers of persons with disabilities are found to be living in substandard conditions (UNEP & UNEP Asia-Pacific, 2015).

By all indications of the region's present situation, it is obvious that another generation of regional children and youths in the Asia and Pacific region is experiencing a high risk of life hardship, lack of preventable disabling conditions, lack of accessible and affordable health care and rehabilitation services, and lack of education and is subject of different types of exploitation. These facts indicate the need for a deeper understanding of the issues faced by the poorest of the poor and most vulnerable people with disabilities in over 52 countries and related territories where there is also a dire need to implement socioeconomic development projects to improve the living conditions of vulnerable populations, among them, individuals with significant disabilities in Asia and the Pacific region.

Disability Statistics in Asia and Pacific Region

The prevalence of disability in the region is an important epidemiological activity to look into because it can provide a clear picture of disability statistics. According to the World Health Organization's (WHO) global estimation, one out of ten persons has some type of disability, and in the Asia and Pacific region, it is estimated that there are over 650 million people with disabilities, comprising two thirds of the world's disabled population who have a diagnosed disability. Among them, over 80% are estimated to live in the rural areas of developing countries of the region. However, these figures are not substantiated by any statistic methods, as collecting internationally comparable data on disability, in particular in rural isolated areas, is a challenging task for local governments and international partners (WHO, 2015).

In the majority of the countries and areas of East Asia and the Pacific region, similar to other countries in the developing world, it is difficult to ascertain the prevalence of disability. A major concern for policy makers and personnel working in the field of disability formulating policies and implementing programs to meet the needs of persons with disabilities is a deficiency of disability statistics and inaccuracy of whatever data is available. According to WHO (2011), in regional areas where disability data are seldom collected, it is usually because of the low priority accorded to disability issues by the relevant national agencies compounded by the multiple barriers that may exist to locate and confirm disability cases among the population.

The existing reports and data indicate that disability issues represent a global burden, and it is estimated that there are over one billion people with disabilities in the world. This corresponds to about 15% of the world's population (WHO, 2012). In the Asia and Pacific region, disability is a significant burden due to the lack of resources to be allocated to deal with disability issues.

Disability is more common among children, women, young adults, and the elderly who are among the poorest populations. The WHO (2013) further indicated that people with disabilities face widespread barriers in accessing services in health care, rehabilitation services, education, and accessible transportation including employment opportunities.

The number of people with disability in the region is expected to rise over the next decades due to civil unrests and wars, population aging, natural disasters, chronic health conditions, road traffic injuries, poor working conditions, and other factors (WHO, 2012). People with disabilities generally have poorer health, lower education achievements or no access to education at all, fewer economic opportunities, and higher rates of poverty. This is largely due to the barriers they face and living situations, rather than their disability. Disability is not only a public health issue but also a human rights and socio-development issue. Disability issues in the region have been studied and analyzed by numerous international professionals and local civil and governmental organizations. The WHO, as part of the United Nations system, has made significant efforts to support regional UN member states to address disability. These multinational efforts are guided by the overarching principles and approaches reflected in the WHO global disability action plan 2014–2021 (2014), The *World Report on Disability* (2011), and the UN Convention on the Rights of Persons with Disabilities (2006).

According to the WHO global disability action plan 2014–2021, the *World Report on Disability*, and the Convention on the Rights of Persons with Disabilities, despite the constant increase in their numbers, persons with disabilities tend to be unseen, unheard, and uncounted. This situation is no different in the Asia and Pacific region with its diverse populations of persons with disabilities. They are often excluded from access to education, employment, social protection services, and legal support systems and are subject to disproportionately high rates of health issues and extreme poverty. Persons with disabilities continue to face both barriers in their participation as equal members of society and are violated of their most basic human rights (WHO, 2014).

An International Perspective of the Etiology of Disability

According to the World Health Organization (2011), "disability" can simply be defined as the umbrella term for impairments, activity limitations, and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (WHO, 2011).

Disability is part of the human condition, and it is perceived and treated differently in different parts of the world. Almost everyone will be temporarily or permanently impaired at some point in life, and those who survive to old age will experience increasing difficulties in functioning. Most extended families have a family member with a disability, and many nondisabled people take responsibility for supporting and caring for their relatives and friends with disabilities (Ferguson, 2001; Mishra & Gupta, 2006; Zola, 1989). Every era has faced the moral and political issue of how best to include and support people with disabilities. The implications of disabilities will become more acute as the demographics of societies change and more people live beyond the expected life span to advance old age (Lee, 2003).

We are often challenged by the question: What is a disability? Based on numerous sources, while applying a global perspective, we can state that a disability is a condition or function judged to be significantly impaired relative to the usual standard of an individual or group. The term is used to refer to individual functioning, including physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness, and various types of chronic disabling diseases (Quinn & Degener, 2002).

Disability is conceptualized as being a multidimensional experience for the person involved. There may be effects on organs or body parts, and there may be effects on a person's participation in areas of everyday life. Correspondingly, three dimensions of disability are recognized by the International Classification of Functioning, Disability and Health, also known as ICF. The ICF is a classification of the health components of functioning and disability: *body structure and function* (and impairment thereof), *activity* (and activity restrictions), and *participation* (and participation restrictions) (WHO ICF, 2001). The World Health Organization's Assembly held on May 22, 2001, approved the International Classification of Functioning, Disability, and Health and its abbreviation of "ICF." The ICF classification also recognizes the role of physical and social environmental factors in affecting disability outcomes and defining what a disability is in different contexts such as individual and socioeconomic and social inclusion (WHO, 2011).

As indicated above, disability is complex, dynamic, multidimensional, and contested. Over recent decades, movement of persons with disabilities and their organizations together with numerous researchers from the social, rehabilitation, and health sciences (Barnes, 1991; Charlton, 1998; Driedger, 1989 and McConachie, 2006) have identified the role of social and physical barriers in disability. A positive outcome of the interpretation of the ICF, at the international level, has had a significant transition from an individual, medical perspective to a structural, social perspective which has been described as the shift from a "medical model" to a "social model" in which people are viewed as being disabled by society rather than by the condition of their bodies (Oliver, 1990).

While considering the etiology of disability, first we need to acknowledge the diversity and complexity of disability. The disability experience resulting from the interaction of health conditions, personal factors, and environmental factors varies greatly. Persons with disabilities are diverse and heterogeneous, while stereotypical views of disability emphasize wheelchair users and a few other "classic" or common groups such as people with visual impairment or blindness and people who are hearing impaired or deaf (Dalal, 2006). Disability encompasses the child born with a congenital condition such as cerebral palsy (CP) or the young soldier who loses his leg to a land mine or the middle-aged woman with severe arthritis or the older person with dementia, among many others. Looking into the etiology of disability, we come to understand that health conditions can be visible or invisible; temporary or long term; static, episodic, or degenerating; and painful or inconsequential. It is also important to note that many people with disabilities do not consider themselves to be unhealthy (Watson, 2002). For example, 40% of people with severe or profound disability who responded to the 2007–2008 Australian National Health Survey rated their health as good, very good, or excellent in spite of whatever disability they may have been diagnosed to have by the medical healthcare professional (National Health Survey, 2009). This demonstrated the continuation of life with a disability without major concerns of being "unhealthy" or perceived as being "sick."

Generalizations about "disability" or "people with disabilities" can be misleading. Persons with disabilities have diverse personal factors with differences in gender, age, socioeconomic status, sexuality, ethnicity, or cultural heritage. Each has his or her personal preferences and responses to disability (London Disability Rights Commission, 2007). Also while disability correlates with disadvantage, not all people with disabilities in all world regions are equally disadvantaged. A good example of disability-based experience is the unique interaction of the disability and the person worldwide. Women with disabilities experience the combined women with disabilities experience and disadvantages associated with their gender as well as the disability and may be less likely to have a similar lifestyle as nondisabled women (Nagata, 2003; Rao, 2010). People who experience mental health conditions or intellectual impairments appear to be more disadvantaged in many settings than those who experience physical or sensory impairments (Roulstone & Barnes, 2005). People with more severe impairments often experience greater disadvantage, as shown by evidence ranging from the Asia and Pacific region and employment data from various countries in the region in rural and urban settings. Conversely, wealth and social status can help overcome activity limitations and participation restrictions for some but not for many across the region (Grammenos, 2003). The etiology of disability and its definition can give us information about the medically diagnosed type of disability, symptoms, prognosis, and health-related consequences affecting the life course of the person, but it cannot tell us much about other important factors of disability such as culturally based perceptions of disability, characteristics of the person, living conditions, and rehabilitation outcomes, if rehabilitation services were to be provided.

Cultural Implications of Disability and Rehabilitation Practice

Culture has been conceptualized and defined by scholars as the multiple historical, sociopolitical, and organizing systems of meaning, knowledge, and daily living that involve patterns of being, believing, bonding, belonging, behaving, and becoming which provide foundational frames for developing worldview, interpreting reality, and acting in the world for a group of people who share common ancestry, social location, group identity, or defining experiential context. All of these factors are very evident in the diversity of the Asia and Pacific region. This concept can be applied to individuals or intersectional subgroups, where particular elements of a cultural system may be embraced, internalized, and expressed differently. Cultural systems emerge and transform over time through cumulative and adaptation-oriented person-environment transactions and are maintained and transmitted through collective memory, narrative, and socialization processes. Cultural systems are dynamic while simultaneously being embedded in social and institutional contexts, internalized as patterns of meaning and identity, expressed through actions and relationships, and interactive with coexisting cultural systems that reflect the multiple dimensions of human diversity that carry culture (Chao & Kesebir, 2013).

Cultural factors influence attitudes toward everything that takes place around us, including our attitudes toward disability, persons with disabilities, and rehabilitation practices. The term “handicap” commonly applied to disability is defined in relation to contextual factors that are predominantly cultural. Though the influence of cultural factors is great, often rehabilitation practice and community-based rehabilitation (CBR) programs in the provision of rehabilitation services fail to recognize culture as a major characteristic of the individual or groups with disabilities. Western stereotypes of “community” are used in the planning of many rehabilitation service programs and CBR programs in developing countries whose communities have their own individuality. These programs expose themselves to a higher risk of failure because they tend to conflict, with the cultural factors of the host country or community. An illustration of the significant implications of cultural influences on disability and rehabilitation, in the context of CBR, can explain the importance of culture, disability, and rehabilitation. In many developing countries, “individual rights” as expressed in industrialized nations does not exist. Traditionally in these countries, an individual is born in a kinship group, with a network of relationships that involve mutual obligations with regard to religious and economic factors. People look toward their immediate family member for protection, welfare, and help, rather than at the traditional Western types of formal human or social services. Because of this kind of relationship, the process of “empowerment” of an individual in this society is more complex, irrespective of whether he/she is a person with a disability or otherwise. Therefore, during planning of medical or vocational rehabilitation programs, one has to also consider the different aspects of cultural influences in these countries.

According to Yuenwah (2012), the Asia and Pacific region has a rich heritage of values and practices for community self-reliance and balanced resource use. "Gotong royong" (a concept of reciprocity or mutual help, common in Indonesia and Malaysia) and "Saemaul Undong" (an integrated rural development movement initiated in the Republic of Korea and based on the spirit of diligence, self-help, and cooperation) are just two examples.

These cultural resources lend themselves to CBR. They could give fresh impetus to a community-driven, self-help movement for change. This would take us one step closer to correcting a skewed development path that has left in its wake so much inequality and pain. In addressing development issues, be they chronic ones like poverty and inequality or dramatic, newer challenges such as urbanization and population aging, CBR could catalyze a new era of community action for inclusive growth and sustainability.

We also need to look back at previous studies and assessments of the region that set the path for the improvements of today. According to Rehman (1999), the influence of traditional values and religious beliefs on the practice of CBR in the North West Frontier Province of Pakistan illustrates this point very well. Rehman describes how cultural factors influence the outcome of CBR and explains how certain culturally based modifications were introduced in rural areas of Pakistan, to align to CBR services appropriately to the traditions and customs prevalent to the Pakistani rural areas. A review by Coleridge (1993), on the history of "negative attitude" toward people with disabilities, concludes that "attitude" toward people with disabilities was not always "negative" and that historically it had been a mixture of "tolerance" combined with "persecution." These attitudes, however, influence the perception of the causation of disability, reactions toward people with disabilities, disability-related child-rearing practices, education, and vocational rehabilitation of people with disabilities. In another review of cultural influences on planning and providing rehabilitation, Miles (1996) analyzed the reasons for Western misinterpretation of cultural variables and the effects of this misinterpretation on South Asian countries' disability planning.

Cultural factors are described in the broad sense as a set of variables related to tradition, ethnicity, and religion, grouped together into a single entity. This is not different when we describe the culture of people with disabilities in the world's regions. Even across the population of a single country, there are substantial differences in ethnicity, caste, religious practices, and so on, which are recognized by different social laws applying to different groups within the same nation. What seems to be ethically correct behavior in one group of people may not be recognized as such by a different cultural community. The recognition of these kinds of differences in the perception of "normalcy" and "disability" is very important in the case of rehabilitation, since what is considered a "handicap" in one cultural context may be considered normal in another context. For example, Benares, a place of worship in India, had most of its blind people living in their homes and begging in the streets of the town during the day. They could earn more money begging and living at home and preferred to do this, rather than stay in an asylum where begging was forbidden or receiving vocational rehabilitation with the goal of becoming employed. Unless someone who was truly destitute and disabled and unable to earn a living, a person with a disability would not want to seek shelter in an asylum (Miles, 1994). If the Western ideologies related to human rights and community-based rehabilitation are applied in the community of these people who are blind without due regard to the indigenous concepts of community-accepted behavior, this effort would more likely fail in any attempt to implement rehabilitation practice.

Rehabilitation Service Practice

During the past two decades, the World Health Organization (WHO), the International Labour Organization (ILO), and the United Nations

Development Programme (UNDP) have made great efforts to promote a more cost-effective, home-based, and culturally based rehabilitation services delivery system which is designed as a "community therapy program" also known as CBR, in developing countries in particular throughout the Asia and Pacific region. In the beginning, this model-practiced community-located interventions was nearly identical to that of the clinical setting in institutions, dealing primarily with disabling impairments. Gradually, it was recognized that these programs did not produce the desired impact unless the extrinsic cultural factors were recognized and incorporated and goals modified accordingly to each community. In 1994, the UN system organizations, jointly, reviewed CBR practices with a different perspective and emphasized the contributions from external contextual factors (disability, culture, and rehabilitation). The goal of the CBR programs was redefined as integration for persons with disabilities within their communities, rather than an attempt for relief of impairment or disability among disabled persons (ILO, UNESCO, & WHO, 1994). This broader view of CBR in the community development perspective reduces the importance of medical rehabilitation and medical model into a less significant peripheral activity within society.

In the Asia and Pacific region from developed to developing countries to island nations, the aim of this pattern of evolution and development of rehabilitation services has been to increase coverage and to gain access to the required resources from the community. However, there were insufficient efforts at promoting community ownership in these programs. As a result, they were most often practiced with a "top-down" management style and rarely did the practitioners take into account the relevance of sociocultural factors. The rural communities in developing countries are often exposed to severe economic pressures and daily living hardships. During this time, their primary focus shifts to survival and overcoming poverty rather than dealing with disability. This can also be better understood from the explanation of Ranganathananda (1995) about Indian democracy stating that "citizenship" as an identity entailing community responsibility is weak in much of South Asia. The members of the society expect the rulers such as governmental and community leaders to shoulder the entire responsibility of the society, while they consider themselves free of societal responsibilities. In these societies, participation and bottom-up management styles are not practiced and can only be brought about by preplanned strategies.

There are many other specific areas of cultural influences that affect disability and rehabilitation. Many of them have been recognized by different authors practicing CBR in different parts of the world. For example, the Afghan society views "empowerment" in a different light from the Western societies. In Afghanistan as in many Asian countries, "empowerment" of the individual, as seen in the Western context, is perceived as being selfish and undesirable. Being altruistic for the sake of the family and for the larger society has a higher value. The term "empowerment" can at best be interpreted only as a right to access provisions and services on an equal footing as others. Similarly, women in Afghan society remain segregated from men, and "integration" of disabled women into the "community" is perceived in a different context from the Western societies, as an integration into the subgroup of segregated women. Rehman (1999) has written about CBR programs that have been successfully practiced in these conditions, by adopting unusual strategies that were suitable for the cultural context of the country in which the programs operate. Another example is from the CBR program in Rupununi, a Guyanese village, as reported by Pierre (1995). The Rupununi villagers have a rudimentary style of living, which facilitates spontaneous rehabilitation of hearing-impaired people as farmers, fishermen, and cooks and where blind persons can go fishing sometimes. The Rupununi CBR program assimilated ideas from the spontaneous rehabilitation practices that had already existed in this community, to design training materials that were appropriate to their cultural requirements. There are also other reports of traditional "attitudes" which influence the outcome of rehabilitation positively as well as negatively (Khatleli et al., 1995; Thorburn, 1998).

The Asia and Pacific region is a good example of decentralization of rehabilitation services into the community and integration of disabled persons into their society that calls for closer interactions with cultural factors. It is important to remember that rehabilitation is a gradual and long process that cannot escape the influences of local cultural factors, and therefore it is difficult to propose a universal theory for all aspects of rehabilitation, just as it is difficult to have a universal model for interventions in rehabilitation.

The System of Service Delivery in Rural Areas

Living in rural areas in the Asia and Pacific region poses particular challenges for people with disabilities in accessing education, vocational training, and employment opportunities. Dismantling the barriers that rural people with disability face enables them to improve their livelihoods and those of their families and take an active role in rural economic development. The removal of socioeconomic and environmental barrier is of vital importance for the empowering of people with disabilities in rural areas and for rural development (ILO, 2010).

People with disabilities, young and old, who live in rural areas where essential services are often limited or nonexistent face difficulties seldom encountered in urban areas. Access to housing, transportation, employment, educational programs, and specialized health care are some of the challenging issues found throughout the rural parts of the region. It is said that "where there is a will there is a way," but this can be difficult for people with disabilities in particular for those living in isolated rural areas. However, communities can help people with disabilities by looking for ways to partner and creatively use limited resources to provide basic needed services (UNESCAP, 2015).

The regional rehabilitation systems of service delivery are organized and provided by community-based rehabilitation agencies. Community-based rehabilitation (CBR) schemes have been in existence since the early 1960s in many developing countries (Miles, 1985). However, CBR received increased attention by being identified by WHO as an innovative new approach to replace the institution-based approach, alongside the trend of Primary Health Care (PHC) toward the realization of the goal of the Alma-Ata Declaration "health for all by the year 2000" (Lysack, 1992; Nakanishi & Kuno, 1997). At the same time, Tjandrakusuma et al. (1995) developed an approach which focused on the aspect of community participation and included consciousness raising and community organization in its program in Indonesia.

Community-Based Rehabilitation and Other Related Services for People with Disabilities

Community-based rehabilitation (CBR) is a developing concept and approach. Although the first definition of CBR in 1981 by WHO emphasized service delivery at the community level, the importance of the social development aspect was gradually recognized and explained as a "democratization of rehabilitation" in WHO's CBR manual (Helander, 1998). This trend has been developed further, and CBR is defined as follows: community-based rehabilitation is a strategy within community development for the rehabilitation, equalization of opportunities, and social integration of all people with disabilities. CBR is implemented through the combined efforts of persons with disabilities, their families, and communities and the appropriate health, education, vocational, and social services (ILO, UNESCO, & WHO, 1994). Likewise, many CBR practitioners define CBR by including two important characteristics: the appliance of community development approaches, not merely an expansion of rehabilitative service delivery at community level, hence focusing on participation and empowerment of the community including disabled people, and comprehensiveness in terms of programs and participants. There are three approaches to CBR. WHO divides approaches in rehabilitation into three types, institution-based (IB) approach, outreach (OR) approach, and community-based (CB) approach in its manual, and this distinction is accepted widely by CBR practitioners. Nakanishi (1989) contrasts CB and IB/OR from a civil rights movement point of view and emphasizes this distinction in order to clarify who controls the resources, although she recognizes that the differences between these two approaches in practice are primarily a matter of degree rather than their being at either extreme (ESCAP, 1989). On the other hand, Tjandrakusuma (1995) indicated that it would fail to provide a true understanding of CBR to explain CBR as being in a dichotomy with IB, as CBR is neither in opposition to IB nor do they complement each other. CBR should be thought of as an entire continuum, or system, with many different aspects. Although these explanations of approaches seem different, they share the fundamental concept described in the definition of CBR and may be synthesized based on the type of services provided. Basically the services range from an at-home assessment, referral for medical services, physical therapy, and vocational services ranging from literacy to continuing education and skill development for employment. Employment can be found with private industries or with the type of shelter workshops similar to other Western countries.

Community-based rehabilitation (CBR), as mentioned above, is “a strategy that can address the needs of people with disabilities within their communities in all countries. This strategy promotes community leadership and the full participation of people with disabilities and their organizations. It promotes multi-sectoral collaboration to support community needs and activities, and collaboration between all groups that can contribute to meeting its goals” (WHO, ILO, UNESCO, and IDDC (2010). The following are some regional nations that have taken an active action in making improvement in favor of their population with disabilities:

- In the Asia and Pacific region, CBR focuses on enhancing the quality of life for people with disabilities and their families, meeting basic needs and ensuring inclusion and participation to empower people with disabilities to access and benefit from education, employment, and health and to have meaningful social roles and responsibilities and to be treated as equal members of society.
- In regional countries of Bhutan and Myanmar, CBR programs are implemented through the primary health-care system.
- In Nepal, CBR programs are implemented in 35 districts by local nongovernmental organizations (NGOs), with the central government providing funding, direction, advice, and monitoring at the national and district levels.
- In India and Sri Lanka, ministries of social welfare have national CBR programs.
- International migration and disability in the rural areas.
- Strategies to enhance services in the Asia and Pacific region.
- The National Trust Act of India has produced collaboration among a range of nongovernmental organizations (NGOs). In India different NGOs or agencies serve different disability groups, but the lack of coordination between them undermines their effectiveness.
- In Thailand, the national committee which comprises representatives from the department of People with Disabilities Development, medical services, local authority support, and disabled people organizations is the main mechanism of national-level CBR. However, at the community level, the main personnel who take care of people with disabilities are local authorities and community health workers, including international projects and partners (WHO, 2011).

It obvious that the region through its use of CBR has made a tremendous effort to provide the much needed services to persons with disabilities and their significant family members. CBR has made a lot of positive changes in the health, rehabilitation, and well-being of people with disabilities. However, like any program or initiative, adjustment and improvement are always needed, and in this case, it may be more of financial support and better training of personnel providing the services as well as different levels of training the consumers with disabilities and their significant family members in the community.

Barriers to Service Delivery for Persons with Disabilities in Rural Areas

Addressing barriers to service delivery in all regional areas is an ongoing effort of contributions on the part of government's entities and community key players all throughout the region's countries and communities. The challenge of barriers to services becomes greater when addressing the multiple implications to these barriers to service delivery in rural areas also considering costal isolated areas. Some of the efforts to address service delivery barrier issues are the work of disabled people's organizations (DPOs) and private- and government-funded service providers (human services, social protection, health care, and community-based rehabilitation). All regional nations continue to make an effort to put into best practice evidence-based service delivery that will provide positive outcomes for the people who need the services. Some of the guiding points to address barriers to service delivery are:

- All groups in society should have access to comprehensive, inclusive health care. Labeled as a major effort is the policy and programs identified by Development for All: Toward a disabilityinclusive Australian Aid Program 2009–2014, which identifies possible solutions (Canberra, 2009), including the following major key points.
- Targeted interventions can help reduce inequities in health and meet the specific needs of individuals with disabilities (Rauch, Cieza, & Stucki, 2008).
- Empowering people with disabilities to maximize their health by providing information, training, and peer support. Where appropriate, family members and care takers should be included.
- Groups who require alternative service delivery models should be identified, for example, targeted services and care coordination, to improve access to health care with significant effort to serve and care for rural populations.
- Community-based rehabilitation should be promoted to facilitate access for people with disabilities to existing services.

Addressing human resource barriers, such as qualified personnel and sensitivity training to work in the field of CBR, is also equally important as indicated by the UN Convention on the Rights of Persons with Disabilities (2006).

Human resource barriers can be overcome by:

- Educating, training, and preparing service delivery worker to work with people with disabilities and their immediate family members in whatever setting they may reside (rural, costal island, or urban)
- Integrating disability education into undergraduate and continuing education for all healthcare professionals
- Involving people with disabilities as providers of education and training wherever possible
- Providing evidence-based guidelines for assessment and treatment emphasizing patient/person-centered care
- Training of community workers so that they can play a role in screening and preventive healthcare services

Filling the existing gaps in data and research in the Asia and Pacific region is very important in order to provide and enhance service delivery to all regional populations of service providers and recipients of the services. According to Erie and Loeb (2006), this is an issue that has also been observed and managed to a certain extent in other world regions and provides a good example to duplicate service delivery practices.

Recommendations provided to address these issues are:

- Ensuring use of the ICF, to provide a consistent framework in health and disability-related research
- Encouraging research on the needs, barriers to general health care, and health outcomes for people with specific disabilities

- Establishing monitoring and evaluation systems to assess interventions and long-term health outcomes for people with disabilities
- Including people with disabilities in data gathering for research and research on general healthcare services

The above recommendations and the regional decade activities are promising to make more changes to benefit the regional population of people with disabilities.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the Asia and Pacific Region

Many years of work and collaboration of international organizations of people with disabilities and the collaboration of UN state members had the most significant outcome in the form of an international convention with a set of rules that countries can adapt to their regional public policies, laws, and regulations. The UN Convention on the Rights of Persons with Disabilities (CRPD) is the most rapidly approved United Nations human rights convention in history, a feat that demonstrates the global commitment to disability. The purpose of the CRPD is to promote, defend, and reinforce the human rights of all persons with disabilities. The Convention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated and where protection of rights must be reinforced. Therefore, the Convention serves as the legal framework for policy making and advocacy (UNCRPD, 2006).

The Convention on the Rights of Persons with Disabilities and its Optional Protocol (A/RES/61/106) was adopted on 13 December 2006 at the United Nations Headquarters in New York and was opened for signature by the UN members states on 30 March 2007. The Convention follows decades of work by the United Nations and international nongovernmental organizations (INGOs) to change attitudes and approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as “objects” of charity, medical treatment, and social protection toward viewing persons with disabilities as “subjects” with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members and contributors of society. The Convention as it is written and known focuses on the intention to have:

> A comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities will make a significant contribution to redressing the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities, in both developing and developed countries. (United Nations Convention on the Rights of Persons with Disabilities. Preamble, 2006)

While many countries worldwide have begun to take action to improve the lives of people with disabilities, much remains to be done. The evidence in the *World Report on Disability* (2011) suggests that many of the barriers people with disabilities face are avoidable and correctable and that disadvantages associated with disability can be overcome. The report calls on governments to review and revise existing legislation and policies for consistency with the Convention on the Rights of Persons with Disabilities (CRPD) and to develop national disability strategies and action plans that will enhance the quality of life of persons with disabilities worldwide.

Policymakers at all levels have a responsibility to ensure that persons with disabilities enjoy all human rights and freedoms on an equal basis with other members of society. Worldwide efforts have been made by grassroots organizations such as disabled people’s organizations (DPOs) and governmental ministries' entities at the regional, local, and the United Nations international levels. With 166 country ratifications since the adoption of the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD) in 2006, the CRPD is the most valuable United Nations human rights convention in history, an accomplishment that demonstrates the global commitment to disability. It is notable to indicate that the Asia and Pacific region has been very involved from the very beginning of drafting the Convention in order to make sure that their regional countries will support and make the necessary changes for their communities. The contribution of the CRPD has also reinforced regional efforts like the extension of a decade to continue the work to raise awareness about disability and enhance the quality of life of persons with disabilities in the region.

The Asia and Pacific Decade of Persons with Disabilities (2013–2022)

In Asia and the Pacific, efforts to implement the rights of persons with disabilities have been strengthened by the *Incheon Strategy to "Make the Right Real" for Persons with Disabilities* in Asia and the Pacific countries. These are the world's first set of regionally agreed disability-inclusive development goals. The Incheon Strategy was the outcome of governments of the UN Economic and Social Commission for Asia and the Pacific (ESCAP) region gathered in Incheon, Republic of Korea, from 29 October to 2 November 2012 to chart the course of the new *Asian and Pacific Decade of Persons with Disabilities* for the period of 2013–2022. At this conference, they were joined by representatives of regional governments and civil society organizations, including organizations of and for persons with disabilities. Also in attendance were representatives of intergovernmental organizations, development cooperation agencies, and the United Nations system. The high-level intergovernmental meeting on the Final Review of the Implementation of the Asian and Pacific Decade of Disabled Persons, 2003–2012, was organized by ESCAP and hosted by the Government of the Republic of Korea. The meeting marked the conclusion of the Asian and Pacific Decade of Disabled Persons, 2003–2012, and launched the new Decade 2013–2022 (UNESCAP, 2012). The Decade 2013–2022 continues to work and has made some noticeable improvement in the way that countries enhance their local social policies and promote the contributions and abilities of persons with disabilities. More significant work is expected and final outcomes of this decade.

Challenges and Opportunities: Attitudinal, Social, Government, Familial

Where there are challenges, new opportunities can be created. The issue of attitudes toward disabilities depends greatly on the cultural believes of the social group. Society changes its views of disability becoming burdensome as they continue to see people with disabilities functioning and contributing to society even under the most hardship conditions. Governments have begun to adjust their resources and become more inclusive of people with disabilities in society. Consequently, families are also benefited by providing effective care and support to their family members with disabilities. They are also in agreement with new policies and programs in favor of people with disabilities. Disability-related activities in the region can demonstrate the changes taking place (ESCAP, 2016).

Activities on disability in the Asia and Pacific region:

- Ten countries in the region have national plans for disability prevention and rehabilitation.
- Since 2003, employment opportunities for people with disabilities have been reviewed among member states, representatives of private industry sectors, nongovernmental organizations (NGOs), the International Labour Organization (ILO), and WHO.
- Regional deafness prevention and alleviation activities have significantly progressed since

2005 and have moved forward for integration in community-based rehabilitation programs.

- The WHO Regional Office for Southeast Asia, as part of the WHO Task Force on Disability formed in 2008, has raised awareness on CRPD with country offices and Ministry of Health and Family Welfare and social protection through several briefings and seminars creating models for best practices.
- Major technical units have integrated disability in the work of the units creating an improved technological access by people with disabilities. The WHO Regional Office building is the first WHO building to have completed Disability Access Audit and is disability friendly.

Recommendations to the UN member states of the WHO Asia and Pacific region:

- Review and revise existing regional and national legislations and policies for consistency with the CRPD, and review and revise compliance and enforcement mechanisms.
- Review mainstream and disability specific policies, systems, and services that will identify gaps and barriers, and plan actions to overcome them.
- Develop a national disability strategy and action plan that are culturally based, establishing clear lines of responsibility and mechanisms for coordination, monitoring, and reporting across all societal sectors.
- Regulate service provision by introducing service standards and by monitoring and enforcing compliance.
- Allocate adequate resources to existing publicly funded services, and appropriately fund the implementation of the national disability strategy and plan of action.
- Adopt national accessibility standards and ensure compliance in new buildings, in transport, and in information and communication.
- Introduce measures to ensure that people with disabilities are protected from poverty and benefit adequately from mainstream poverty alleviation programs.
- Include disability in national data collection systems. Provide disability disaggregated data wherever possible, and consider the use of International Classification of Functioning, Disability, and Health (ICF) in the national data system.
- Implement communication campaigns to increase public knowledge and understanding of disability, and provide channels for people with disabilities and third parties to report and log complaints on human rights issues and laws that are not implemented or enforced.
- Adopt CRPD as a framework and CBR as main strategies for multisector activities to address disabilities (WHO, 2016).

These actions and opportunities to improve the delivery of services to people with disabilities and their family members are an ongoing effort that needs to be consistent and effective. As in any situation of human service provision, the major challenges are proper funding, administrative knowledge, and quality of services. Other challenges related to how society perceives disability and governmental support to the population in need can be overcome by enforcing laws and regulations that are already in place and that will make the case of disability a priority for social justice and socioeconomic development.

Summary

The results of the comprehensive research studies during the past years have clearly indicated the diverse experiences of people with disabilities in the Asia and Pacific region. There is a strong and consistent evidence to validate the association of disability with higher levels of poverty and deprivation and sufficient and vulnerable livelihoods from all age groups and cultural and ethnic backgrounds which resulted in findings of substandard living conditions of extreme poverty. The results of actions of research underscore the urgency of policy action to address the specific livelihood needs of people with disabilities, especially those living in poverty in rural and urban areas. There is also ample evidence that through the contribution of many international and regional entities, a lot of work has been done which is still undergoing with the purpose to alleviate the situation of disability in the region. The Asia and Pacific Decade of People with Disabilities, 2013–2022, is a fresh opportunity for collective action to remove barriers to the participation of persons with disabilities in the everyday life of their communities. This collective action requires financial support and commitment from all government entities in the region and their international partners as well as their local community partners in order to provide comprehensive education, community-based rehabilitation, medical and vocational rehabilitation, and employment support opportunities to individuals with disabilities. Furthermore, the work, guidance, and participation of people with disabilities and their organizations should be an inclusive priority for the advancement of the region. This approach will bring all stakeholders closer to the goal of reaching equalization of opportunities for all its citizens in the region.

Learning Exercises

1. Compare and contrast the US Americans with Disabilities Act and the UN Convention on the Rights of Persons with Disabilities in reference to the protection of the civic and human rights of persons with disabilities and the promotion of the equalization of opportunities for individuals with disabilities.
    - What are the strengths of each?
    - What are the implications for policies and allocation of resources?
    - How can these two cornerstone documents make a definite change for people with disabilities and worldwide societies?
2. Discuss the cultural implications of the US American and Asia and Pacific region cultures regarding the perception of disability and attitudes toward disability.
    - Does culture affect how disability is perceived, understood, and treated?
    - Have these distinctive societies become more paternalistic?
    - What can they learn from each other?
3. CBR is perceived as an effective program for working with individuals with disabilities in the Asia and Pacific region.
    - Could this concept be applied in the USA?
    - What are the differences, if any, between the two systems?
    - How similar or different is rural rehabilitation in the US America?

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18

Disability and Vocational Rehabilitation in Rural and Remote Australasia

Elias Mpofu, James Athanasou, Ashley Craig,
and Shane Heasley

Overview
Vocational rehabilitation services in Australia

- Legal and policy instruments
- Service provision approaches

Significance of work and employment to healthy rural living

- Types of occupations

Disability in rural and remote settings

- Strategies to enhance service delivery

Improving rehabilitation counsellor skills and interventions

- Culturally safe practices with indigenous groups
- Strengthening – social and technological networks
- Research needs
- Improving motivation and optimism in people with disabilities
- Reliable and valid vocational rehabilitation service protocols

Summary and conclusions

Learning Objectives
By the end of this chapter, you should be able to:

- Outline the legislative and policy foundations of rehabilitation in Australasia.
- Specify the frameworks for the vocational rehabilitation services to rural and remote Australasian settings.
- Examine any links between vocational rehabilitation services and a unique occupational ecology of rural Australasia.

E. Mpofu (✉)
Department of Rehabilitation and Health Services, University of North Texas, USA

Department of Educational Psychology, University of Johannesburg, South Africa

Faculty of Health Sciences, University of Sydney, Cumberland Campus, Lidcombe, Australia
e-mail: Elias.Mpofu@unt.edu; empofu@uj.ac.za; elias.mpofu@sydney.edu.au

J. Athanasou
Health Sciences, Discipline of Rehabilitation Counseling, The University of Sydney, Lidcombe, NSW, Australia

A. Craig
Kolling Institute of Medical Research, The University of Sydney, St. Leonards, NSW, Australia

Royal North Shore Hospital, St. Leonards, NSW, Australia

S. Heasley
C/G McKinnon, Putarura, South Waikato, New Zealand

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- Identify and evaluate the feasibility vocational rehabilitation service qualities that would be appropriate for indigenous people of Australasia.
- Discuss strategies to improve vocational rehabilitation service delivery in rural Australia.

Introduction

Australasia comprises Australia and New Zealand and islands or territories. Australia comprises a vast continent of 2.9 million square miles with 85% of its population of 23 million residents along the South and Eastern coastal areas. About a third of Australia's population lives in rural or remote areas (Australian Bureau of Statistics, ABS, 2010). The Australian Bureau of Statistics (2001, 2010) defined rural and remoteness to be areas with a population census of 1–199, peri-urban communities as those with a population of 200–999 and urban as with a population census of 100,000. In Australia, common perceptions of the term "rural" could range from rural farming areas, remote areas and desert to non-metropolitan (Humphreys et al., 2012).

Comparatively, New Zealand is an archipelago comprised of two main islands, many smaller islands, inlets and inland and oceanic waters. It is a smaller nation, with a population of 4.5 million. The North Island is New Zealand's most populous island, with a population of around 3.5 million over an area of approximately 44,000 square miles. The South Island, the larger of the two at approximately 58,000 square miles, is divided longitudinally by an alpine range and is home to just 1 million people. Rural in the New Zealand context is divided into four categories defined by levels of interaction and dependence on nearby urban areas: rural area with high urban influence, moderate urban influence, low urban influence and highly rural/remote (Statistics New Zealand, 2006). Statistics New Zealand defined rural centres as those with populations of 300–999; and to distinguish between true rule dwellers and others in rural settlements or towns. A rural settlement with high urban influence will have significant dependence on urban centres for employment, with much of the population travelling to engage in employment. About 12% of the population of New Zealand live in rural areas with high urban influence and 3% live in rural remote areas (Statistics New Zealand, 2008).

Nonetheless, despite the huge differences in land mass, the two countries in their rehabilitation and healthcare provisioning are significantly influenced by geography with availability and access of services lower in the rural and remote regions compared to urban centres. For both countries, comparatively, highly rural or remote areas have smaller, largely self-employed populations with little dependence on urban areas for employment. People with disabilities in rural and remote Australia therefore face a double disadvantage with respect to lack of employment opportunities associated with rural living as well as lack of vocational rehabilitation services to support their work participation with employment (Gething, 1997).

This chapter considers disability and vocational rehabilitation services in rural and remote Australasia, covering the legal and policy frameworks for vocational rehabilitation in Australasia and the structures for implementation and significance of work and employment to health rural living. It then discusses work opportunity and disability in rural and remote Australasia. This includes vocational rehabilitation service needs and utilisation by the vulnerable and historically disadvantaged indigenous populations of Australasia, significant proportions of who are rural and remote community dwellers. Finally, the chapter considers strategies for the enhancement of vocational rehabilitation services in rural and remote Australasia as well as issues for research and other forms of scholarship.

Vocational Rehabilitation Services in Australasia

Vocational rehabilitation services are designed to provide work access, retention and development support, taking into account the specific disability-related needs of the individual, type of work and occupational environment. Specific vocational rehabilitation services provided in the Australasian region include preparation for working; job search strategies including resume preparation, interview skills training, on-the-job support and employer disability support interventions; small business management and self-employment (Buys, Matthews, & Randall, 2015). Vocational rehabilitation service policies of Australasia are authorised by a number of legal mechanisms.

History and Evolution of Services Vocational rehabilitation has a mixed history starting from a background of charitable relief and evolving through a complex system of social security and compensation. Its development continues to be characterised by long periods of neglect then intense bursts of legislative activity (Mendelsohn, 1979). It floats somewhere between welfare versus compensation.

An early example of a welfare mentality towards disability or injury is one of the founding powers in the 1901 Australian Constitution. In Clause 51 xxiii, the federal government has the power to make laws with respect to invalid pensions for people with chronic illness and disability. A Royal Commission on Old-Age Pensions was conducted during 1905–1906, and in December 1910, the invalid pension replaced a scheme that had operated in one of the states. Subsequent developments are summarised in Table 18.1.

Reflection Exercise

Consider the evolution of rehabilitation support services in Australia as in Table 18.1. What aspects relate to empowerment of people with disability and how? To what extent does the evolution of rehabilitation services reflect partnership with people with disabilities to enhance their vocational participation?

The development of vocational rehabilitation was aided in part by advances in medicine with greater survival rates for those with injuries and chronic conditions. It was also a product of the greater awareness of the community's obligation for war veterans.

A government Commonwealth Rehabilitation Service began around 1948, no doubt in response to the needs of World War II veterans. Charities and specific disability groups, such as Society for the Blind, provided vocational services. A major impetus was the expansion of the Commonwealth Rehabilitation Service development of vocational rehabilitation in response to compensable injuries, and for the most part, this has been the mainstay of the profession of rehabilitation counselling in Australia. New Zealand had an analogous history in the development of vocational rehabilitation services.

Legal and Policy Instruments The Australian Disability Services Act (Australian Government, 1986) makes provision for the availability of services to people with disabilities in rural and remote communities of Australia. This followed a review of services for people with disabilities (Handicapped Persons Review, 1985). The main recommendation from the review was to move away from "sheltered workshops" to that of community integration, especially in relation to employment. Later amendments of the Australian Disability Services Act established standards for disability services.

In New Zealand, access to vocational rehabilitation services is provided for in the case of injury through the Accident Compensation (AC) Act of 2001. Access to vocational rehabilitation for those with non-accident-related disability and mental health issues is managed through the Ministry of Social Development. In 2008 New Zealand ratified the Convention on the Rights of Persons with Disability, building on the work of earlier legislation such as the Bill of Rights Act 1990, which provided people with disability the same legal rights and entitlements as all New Zealanders and protects them from discrimination. The New Zealand government also provided the framework to commence the process to remove the barriers which prevent people with disabilities from participating fully in society (Office for Disability Issues, 2016), and from 2016 this strategy is being reviewed. In addition,

Table 18.1 A chronology of key changes in rehabilitation-related social security and other benefits in Australia

Year	Allowance	Description
1908	Invalid and Old-Age Pensions Act 1908	Invalid pension of 10 shillings per week
1928	Employment injury benefits	Workers' compensation introduced in New South Wales funded by compulsory employer contributions
1948	Commonwealth Rehabilitation Service	An invalid pension was paid for those completing vocational training
1967	Sheltered employment allowance	For those persons who qualified for an invalid pension and were employed in a sheltered workshop
1983	Mobility allowance	For persons unable to use public transport for work or vocational training
1983	Rehabilitation allowance	For those persons assisted through the Commonwealth Rehabilitation Service
1983	Healthcare cards	For those who gave up an invalid pension or sheltered employment to take up open employment – free of income test for 12 months
1983	Rehabilitation allowance	Paid to people undertaking a commonwealth rehabilitation programme and for 6 months after completion of vocational counselling programme
1991	Disability reform package	Disability support pension replaces invalid pension; emphasis on rehabilitation, self-sufficiency, work readiness, incentives to employers for hiring persons with disabilities
1997	Job network	Commonwealth employment service replaced by a subsidised private network of services for jobseekers
2006	Welfare to work reforms	Obligation on welfare recipients to work part-time or to look for work; rehabilitation and workforce re-entry assistance was also provided
2013	National Disability Insurance Scheme	Limited vocational rehabilitation services, emphasis on disability services and case management. Emphasis is on consumer choice as to the services he or she needs in the context life domains of importance to him or her

Source: Australian Bureau of Statistics (1988), Daniels (2011)

the New Zealand government has also adopted strategies to support improved health outcomes for its indigenous people, the Maori. *He Korowai Oranga* is a "high-level strategy that supports the Ministry of Health and district health boards (DHBs) to improve Māori health by interlinking implementation of the New Zealand Health Strategy, New Zealand Disability Strategy, and New Zealand Public Health and Disability Act 2000" (Ministry of Health, 2015). The overall aim of this integrated service strategy is to enable Maori families to maximise their health and well-being (Harwood, 2010).

Service Provision Approaches The three broad approaches in implementing policies to assist people with disability to find and maintain work are a generalised disability support service that operates across the life span, a social welfare system approach that operates for adults with disabilities that seeks to minimise reliance on social security (e.g. reliance on disability pensions) and the maximising of early return to work (Herscovitch & Stanton, 2008; McKenzie, 2016; Rockwell, 1939). In Australia, the demand for more efficient vocational rehabilitation resources is, in part, designed to relieve government fiscal pressures by reducing the number of disability pension recipients.

Employment services under the social welfare system are delivered by a network of contracted organisations that provide direct jobseeking support and placement. Return-to-work rehabilitation services seek to minimise economic risk to both the worker with disability and employer by utilising early intervention strategies (Buys, Matthews, & Randall, 2010; Heads of Workers Compensation Authorities Australia and New Zealand, 2015; Safe Work Australia, 2011). The transportability or use of these vocational rehabilitation service models to rural and remote Australasia community settings is unknown.

In Australia vocational rehabilitation services are provided at both the state and federal government levels. There is a degree of complementarity in service provision for persons with a disability in

Australia, with a split between vocational and community living rehabilitation services. The federal government has primary responsibility for employment services in relation to disability. The state governments, on the other hand, deal mainly with allied areas such as family support, housing, community living issues or community services. This is unlike in New Zealand where vocational rehabilitation services operate as the responsibility of the central government, with local government having little responsibility for the support and rehabilitation of those with disability, injury or mental health issues. Delivery of these services is undertaken at a community level, with government organisations, not-for-profit organisations and private enterprise, all being represented in the market of vocational rehabilitation service providers. However, the implementation of these vocational rehabilitation services among Australasian rural and remote communities is questionable, with widespread defunding of local or regional social services by the central governments and consequent attrition of services (Alston, 2002). Furthermore, rural to urban migration continues to deplete the human resource base of rural and remote Australasia, including vocational rehabilitation provisioning. Moreover, many small rural towns, some of which housed occupational rehabilitation services, increasingly are reducing to ghost towns due to attrition of population to the larger urban centres, further adding to the scarcity of employment and work support services (Alston, 2000). The service gaps would include in the provisioning of vocational rehabilitation services.

Significance of Work and Employment to Healthy Rural Living

Work participation makes for health and wellbeing with disability through the latent role functions that work engagement provides (Janlert & Hammarstrom, 2009). Latent roles are those the enactment of which adds to meaningful living and interconnectedness with social others, providing structure to everyday activities. In rural and remote communities with their sparse populations, work role-related routines become even more significant to personal identity and functioning, as dwellers have limited access to social amenities. In other words, the supplemental social and infrastructural amenities often taken for granted in urban centres are typically lacking or constrained so that work engagement is the primary role to interact with others. But, formal work positions are less prevalent in rural and remote regions compared to urban centres (ABS, 2012; Fragar et al., 2010) so that people with disability in rural and remote settings are at elevated risk of unemployment (ABS, 2001; AIHW, 2005). Furthermore the sparse availability of vocational rehabilitation services in rural and remote Australasia would disadvantage those who might benefit from such services (Gittoes, Mpofu, & Matthews, 2011; Pelling & Butler, 2016).

Unemployment on its own is significant risk to health status, while long-term lack of work participation could result in disability (Murphy & Athanasou, 1999). For instance, unemployment is associated with poorer mental health due to social isolation, as well as from the loss of a work role personal identity, important to a sense of meaningfulness to life (Fragar et al., 2010; Waghorn, Collister, Killackey, & Sherring, 2007). For instance, in a study by Fragar et al., unemployed or permanently unable to work rural and remote New South Wales (Australia) residents were shown to have significantly higher levels of psychological distress when compared to those employed or retired. However, rural and remote community dwellers may also be so work engaged as to neglect their healthcare needs and which, if unattended to, could also result in long-term disability and unemployment (McGrath, 2015). For instance, they may be averse to seeking the external help of community outsiders who may be vocational and health professional counsellors (Pelling & Bulter, 2016).

Types of Occupations Rural and remote Australasia is heterogeneous in regard to work role opportunities and occupations (ABS, 2001; AIHW, 2005; Fragar et al., 2010). Summary data on paid employment positions in rural and remote Australia and New Zealand could not be accessed. However, the study by Fragar et al. is the major exception. NSW is typical of the more populous states of federal Australia in having great areas of rural and remote territory with very sparse social services (Gething, 1997).

Fragar et al. (2010) reported 87% of 2639 residents of a rural and remote region of NSW were in paid employment. About four-fifths of the 13% not in paid employment from the Fragar et al. study were retirees (*n* = 796) or permanently unable to work (n = 151) with the rest being students or carers (*n* = 143) or unemployed (*n* = 52). Statistics New Zealand (2001) reported, in highly rural/remote areas, the labour force participation rate was 76.7% in the South Island and lower in the North Island at 71.2%. The rate of self-employment in highly rural/remote areas at this time was twice the national average at 26.1%, where those who were paid employees were just 48.6% compared to the national average of 77.2%. These data suggest that employment participation is challenged in a rural and remote region of Australia and New Zealand and that vocational rehabilitation services would be an important resource for workers in this regional setting.

A question of interest to scoping the likely needs of vocational rehabilitation services in a typical rural and remote Australasian region is the types of occupations available and their prevalence. Based on the Australian and New Zealand Standard Classification of Occupations (ANZSCO) (ABS, 2009), Fragar et al. (2010) documented the title (and proportion) of paid employment positions in rural and remote New South Wales (NSW). These were as follows: clerical, administrative and sales workers (.19); occupation not specified (.14); farmers and farm managers (.12); machinery operators, drivers and labourers (.10); other managers (.09); education professionals (.09); other professionals (.08); technicians and trade workers (.07); other community and personnel service workers (.06); and health professionals and health welfare workers (.06). From these data it is apparent that service-related professions (clerical, administrative and sales workers; technicians and trade workers and other community and personnel service workers) are the most prevalent, accounting for about 31% of paid employment positions, followed by farming-related occupations (farmers and farm managers, machinery operators, drivers, labours) at 24% of the positions and closely followed by education, health and other professional positions at 23% of the positions. A significant minority of paid employment (14%) comprises occupations not specified. While these figures are based on only one region of Australia and may not be representative of the prevalence of paid employment positions in Australasia, they nevertheless provide for a nuanced view that occupations and employment positions in a major rural and remote region of Australia are other than farming activity and in fact service oriented (see also Alston, 2000).

The prevalence of "other unspecified" occupations in rural and remote NSW regions suggests the likely prevalence of temporary and opportunity positions that are downstream to other major occupations. The high proportion of rural and remote community residents reporting to be retired (30%) or permanently unable to work (6%) may occur partly from a lack of vocational rehabilitation services for employment retention or continuation and also from a lack of alternative or viable work opportunities with rural living. Finally those self-reporting as unemployed were not necessarily without any form of employment – only not in paid employment. Many of the women working in Australian family farms may not consider themselves in paid employed positions, even though they have significant work participation (Alston, 2000; Fragar et al., 2010), and some may require vocational rehabilitation services. This situation is not dissimilar in New Zealand, where unpaid family workers in highly rural and remote areas were at 9.5% (Statistics New Zealand, 2001). It is unclear from the study by Fragar et al. as to what proportion of those in retirement or unable to work or unemployed were with disability or for disability-related reasons.

Research Review Question

List the key findings of the Fragar et al., study as described above. What are the major strengths and limitations of the study for informing vocational rehabilitation services in Australia? How might the study have been conducted to enhance its informational value to vocational rehabilitation services design and implementation in Australia?

Disability in Rural and Remote Settings

About 20–25% of the Australia's 7 million people living in rural and remote Australia have a disability (Australia Bureau of Statistics, 2009). A comparable prevalence rate has been reported for New Zealand, where 25% of the national population are reported to have a disability of some description, with rural centres such as Northland (29%) and Taranaki (30%) experiencing higher rates of disability than the national average and urban areas such as Auckland (19%) reporting lower figures (Statistics NZ, 2013). Disability among rural and remote community dwellers also varies by sex. As an example, disability is 20–30% more prevalent among men in the rural and remote areas compared to the urban centres (National Rural Health Alliance, 2009). It is unclear as to how rural living is a contributing factor to the high prevalence of disability among men in rural and remote areas and whether men with disability tend to move to rural and remote areas. Nonetheless, across jurisdictions, people in rural and remote regions carry significant risk from avoidable disability due to inadequate or inaccessible healthcare services as well as to longer distances from comprehensive healthcare centres, poorly developed health infrastructure and a scarcity of rehabilitation counselling or psychological services in such settings (Gittoes et al., 2011; McGrath, 2015; National Rural Health Alliance Inc., 2013). For those with advanced age and with chronic illness and disabilities, rural living offers fewer infrastructural supports, presenting significant health and mobility hardship to residents and their families (Winterton & Warburton, 2011).

People with disability in Australia experience a disproportionate level of unemployment compared to the general population (e.g. see Fig. 18.1).

Rural and remote area dwellers with disability carry significant limitations to their employment capacity. The work role marginalisation of people with disability also in part arises from their vulnerability to becoming chronically fatigued and being susceptible to secondary mental health conditions (Craig, Tran, Wijesuriya, & Middleton, 2012; Craig et al., 2015a). For instance, in a study by Craig et al., people with a disability reported higher levels of chronic fatigue than non-disabled, to the point where they would be workforce challenged (Craig et al., 2012). Those with a disability or unemployed had rates of probable psychological disorder ranging up to a very high and disturbing 70% (Fragar et al., 2010). The stressors from living with disability in rural and remote regions might in themselves increase risk for fatigue and mental health conditions, which will certainly impact their vocational lives.

There is evidence to suggest that rehabilitation service design and implementation might explain employment outcomes with disability than rurality or geographical location (Harradine et al., 2004; Mpofu, Craig, Millington, Murphy, & Dorstyn, 2015). For instance, Harradine et al. concluded from their 2-year longitudinal study that return-to-work outcomes were similar among NSW rural and urban residents with traumatic brain injury. They ascribed the equity of return-to-work outcomes to implementation of an integrated rehabilitation service network across inpatient, outpatient and community outreach care settings. But inter-agency cooperation is least likely in rural and remote Australia, where there are very few disability and rehabilitation providers in the first place, in addition to poorer infrastructure and high professional staff turnover.

Research Review Question

Construct a chart on employment participation rates with and without disability as in Fig. 18.1 for a country setting you are familiar with and spanning the same time period. How do employment rates in the country setting you are familiar with compare to those for Australia? What may explain any similarities or differences you observe?

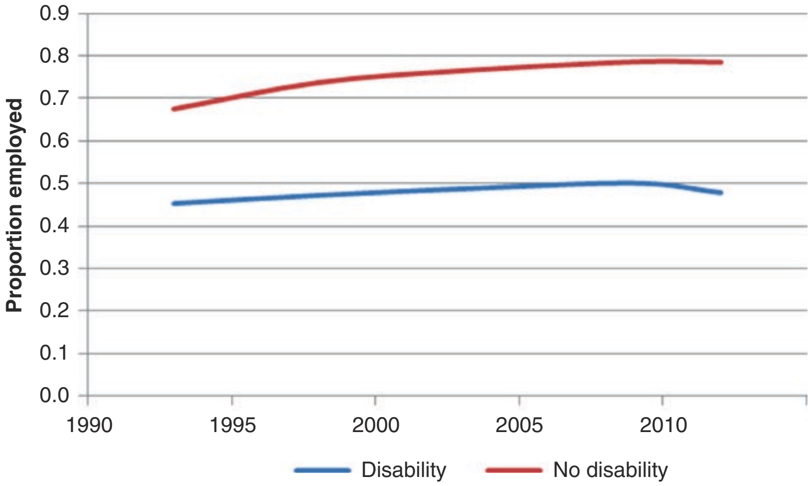

Fig. 18.1 Employment rate for persons with and without a disability in Australia, 1998–2012

Work and Disability in Rural and Remote Australasia

As previously noted, there is evidence to suggest that residents of rural and remote communities of Australasia have lower work or employment opportunities and wellbeing compared to others in urban centres (Alston, 2002; Cheers, 1990). Residents of rural and remote areas also have lower incomes and lower levels of education, adding to their lack of competitiveness for employment positions outside their communities of origin (AIHW, 2007). This would be true especially of impoverished remote and rural communities rather than those with flourishing agro- and/or eco-tourism-related industry.

Australasia presents diversity of work and employment opportunities: agribusiness, ecotourism, cultural tourism with indigenous communities, mining, and related service sectors. The presence and significance of work and employment opportunity in the rural and remote community sectors vary by the specific region. Some rural and remote industries, such as mining, may be a boon for employment for local communities given it usually results in proportionally significant recruitment of local labour. However, this is not always guaranteed, as mining companies may prefer to ferry in a large proportion of their labour force (Carrington & Pereira, 2011). Moreover, the collateral cost of the mining industry to the local agro-industry and eco-cultural tourism from severe contamination of the land, water and resources from pollutants (Franks, Brereton, & Moran, 2010), which if uncontrolled, may become a hidden cause of widespread disability among the rural community dwellers. Extraction industries also have the potential to cause serious damage to eco-tourism, especially when they close, often leaving behind huge unsightly galleys and earthen dump walls from the mining pits. Furthermore, indigenous cultural communities with rich cultural tourism may experience irreparable damage to their historic shrines central to their way of life from large-scale mining activities. Vocational rehabilitation needs and solutions generated by external or migrant resource extractions industry to rural and remote Australia have not been documented.

Vocational rehabilitation services for migrant workers are provided through their human resource departments not available to the local rural populace. With large itinerant workers such as in extraction industries, vocational rehabilitation services should address the mental health needs arising from the workers' diminished sense of involvement or of detachment from local community, which would contribute to occupational, work health and safety risks for work-related injury.

Indigenous Australasians Indigenous people are among the most impoverished in rural and remote Australasia (Alston, 2000). Both Australia and New Zealand have indigenous populations (Aborigine Torres Strait Islander (ATSI) =2% of the population and Maori =15%, respectively) (ABS, 2010; Harwood, 2010). Indigenous people also comprise a significant minority in the rural and remote regions of Australia and New Zealand (8–64% and 15%, respectively; AIHW, 2008; Statistics New Zealand, 2008; Watts & Carlson, 2002). About 24% of ATSI live in remote areas compared to only 1% of the general Australian population (AIHW, 2008).

Indigenous people in both Australia and New Zealand have historical disadvantage in accessing rehabilitation and health services, including vocational or employment services (Kendall & Marshall, 2004, New Zealand Disability Survey, 2013). For instance, Maori, New Zealand's indigenous people, experience a disproportionally higher disability rate of 26% than non-Maori, and a majority experience debilitating mental health and intellectual conditions (New Zealand Disability Survey, 2013). Additionally, ATSI peoples have a rate of mental health and physical disability 6–10 times that of the general population of Australia mostly from interpersonal violence, accidents, falls and self-harm (Dudgeon, Milroy, & Walker, 2014; Keightley, Ratnayake, Minore, Katt, Cameron, White et al., 2009; Kendall et al., 2004, Parker, 2016; Vos, Barker, Stanley, & Lopez, 2007). For example, in the Kimberly region, common causes of traumatic brain injury among the ABTSI were from interpersonal violence (46.5%), horse-riding accidents (14.6%), motor vehicle accidents (10.3%), falls (7%) and self-harm (5.9%). The unemployment rate among indigenous ATSI is estimated at two to three times that of the general population of Australia (Alston, 2000; ABS, 2012); Maori people also experience an unemployment rate twice that of non-Maori New Zealanders (Statistics New Zealand, 2015a). Yet, ATSI and Maori have the lowest rate of utilisation of government social services, including vocational rehabilitation (Kendall et al., 2004; Mauri Ora Associates, 2010). For instance, while Maori people represent around 15.6% of the population, they only account for 11.55% of all accident rehabilitation compensation claims (Mauri Ora Associates, 2010). The lower utilisation of health services and the subsequent impact on health status have been attributed in part to limited access to culturally appropriate services (Harwood, 2010) and the disconnection with cultural identity experienced by many Maori, as a product of increasing urbanisation of Maori. *Te Whare Tapa Wha* is a holistic model of Maori health developed by Dr. Mason Durie in 1998, which identifies four equal foundation stones of Maori health: physical health, spiritual health, thoughts and feelings and the extended family. This model uses the four walls of a house (or whare) to symbolise the equal importance of each construct. Key to the success of this and other related models of Maori health is the need for individuals to have a secure Maori identity and to be connected to concepts central to Maori, such as iwi (one's tribe) (Ratima, Edwards, Crengle, Smylie, & Anderson, 2006). Government initiatives in New Zealand such as Whanau Ora and He Korowai Ora seek to address factors cultural appropriateness (including delivery of wellbeing rather than illness-focused services) in the provision of services, as well as supporting Maori to reconnect culturally. The vocational rehabilitation needs of ATSI and Maori people may be neglected from being excluded from the workforce by meagre opportunities for paid employment in their communities, by cultural insensitivity of services and, if with disability, by the "triple jeopardy" of being with disability while ATSI or Maori and rural living.

Reflection Learning Exercise

The research evidence cited in this section suggests lower engagement by indigenous Australasians with vocational rehabilitation services. Construct and describe a vocational services programme that would engage indigenous Australasians. Say how and why the programme you propose would be successful with indigenous people? How is the programme you proposed similar to and different from what others proposed for use with marginalised population in a country setting you are aware?

Strategies to Enhance Service Delivery

The considerably reduced employment and labour force participation rates in people with disabilities, along with increased barriers to improving vocational rehabilitation in Australia, is a clarion call to invest increased resources into strategies that enhance vocational rehabilitation service delivery and outcomes. Vocational rehabilitation models developed for urban employment settings may not necessarily translate to rural and remote community work settings without significant adaptation (Gething, 1997). Nonetheless, employment participation strategies, which have been shown to have evidence such as integration of vocational services into publicly funded mental health services in Australia, hold promise with rural and remote setting populations.

Other prospect approaches entail constructing tailored employment participation support services responsive to the work or occupational ecology of the specific rural and remote areas and developing incentive schemes that assist the unemployed to establish small business (e.g. www.budget.gov.au/2007-08/ministerial/html/dotars-13.htm). The following strategies to enhance the service delivery and vocational rehabilitation are proposed.

Improving Vocational Rehabilitation Counsellor Skills and Interventions in Australasia

One practical strategy for enhancing service delivery of vocational rehabilitation is to improve vocational counsellor skills and provide effective pragmatic interventions (Buys, Matthews, & Randall, 2010; Matthews, Buys, Randall, Marfels, Niehaus, & Bauer, 2013; Middleton et al., 2014). For instance, Buys et al. (2010) concluded that improving the competency of counselling skills of rehabilitation and vocational case managers and providing interventions with an evidence base shown to translate to the workplace should significantly enhance service delivery and vocational rehabilitation outcomes. Arguably, the efficacy of vocational rehabilitation will be related to effective vocational counsellor skills such as the ability to interact, be empathic and communicate and motivate people with disabilities, as well as the capacity to take into consideration the systemic barriers that people with disabilities face when seeking employment. Australian vocational rehabilitation services offers case services coordination and counselling regardless of employment location (Buys et al., 2010). The rehabilitation counsellors from the Buys et al. study perceived to be with insufficient time for their roles likely from high caseloads and their counselling role would likely be diminished with work role overload.

The training of vocational rehabilitation counsellors working in rural remote areas in cultural knowledge and awareness and cultural sensitivity and security skills would especially be important (Dungeon et al., 2014; National Disability and Care Alliance, 2014). Cultural knowledge and awareness is from learning about a culture and its often unwritten rules of membership. Cultural sensitivity and competence is when cultural knowledge and awareness are appropriately applied in social service provisioning. As referred to rehabilitation service provision, cultural security refers to adoption and use of practices that respect the cultural rights, values and expectations of culturally and linguistically diverse others (Western Australia Department of Health, 2006).

Culturally safe vocational rehabilitation services would be particularly important in the provisioning of vocational rehabilitation services to ATSI and Maori people among other culturally and linguistically diverse groups with rural and remote residence. It is imperative for vocational rehabilitation counsellors from mainstream Australasian culture who numerically outnumber ATSI and Maori to understand the meaning of work and context of employment for these marginalised people (National Disability and Care Alliance, 2014). Culturally secure practices entail an accurate understanding by counsellors not only of the other different culture but of the interaction between cultures that mediates the success of vocational rehabilitation services (Dudgeon, Milroy, & Wakler, 2014). There is no end point in seeking cultural competency as a counsellor – only continuous reflective learning.

Culturally Safe Practices with ATSI and Maori The types and qualities of extant vocational rehabilitation services with ATSI and Maori are largely undocumented (Kendall et al., 2004). Although disparities of rehabilitation and health status among indigenous people compared to non-indigenous people is nothing new and is not simply limited to indigenous populations of Australasia (Harwood, 2010; Wyeth, Derrett, Hokowhitu, & Samaranayaka, 2013), it calls for urgent consideration in livelihood settings in which they are predominantly domiciled. Many ATSI and Maori localities have little to no social or employment support services. Many ATSI and Maori people needing health-related support services may be referrals from other regional communities (Doyle, 2012), adding to their burden to access the same services as other citizens (Bolch, Johnston, Giles, Whitehead, Phillips, & Crotty, 2005). Vocational rehabilitation services policy in Australia should mandate benchmarks of service quality with this historically disposed and vulnerable population. Such benchmarks should seek to not only close the gap in vocational services for ATSI and Maori people but to prioritise cultural safety considerations in the design and implementation of the services (Kendal et al., 2004; Watts & Carlson, 2002). A social justice approach to vocational rehabilitation services with ATSI and Maori is imperative in view of the long history of deprivation, dispossession and cultural violations by state and federal governments.

As an example of culturally safe services with the Maori of New Zealand, the Treaty of Waitangi, New Zealand's founding document, recognises the rights of Maori as partners in the Treaty. Although interpretation of the Treaty can at times be a point of controversy, the principles adopted by the NZ government with regard to health are:

- Partnership: involves working together with iwi, hapū, whānau and Māori communities to develop strategies for Māori health gain and appropriate health and disability services
- Participation: requires Māori to be involved at all levels of the health and disability sector, including in decision-making, planning, development and delivery of health and disability services
- Protection: involves the government working to ensure Māori have at least the same level of health as non-Māori and safeguarding Māori cultural concepts, values and practices (New Zealand Ministry of Health, 2014)

The New Zealand Ministry of Health also has implemented Whāia Te Ao Mārama: the Māori Disability Action Plan 2012–2017 based on the indigenous Whanau Ora approach which places whanau or family systems at the centre. This approach recognises that for many Maori, the extended family is regarded as a source of strength, support, wisdom and identity (O'Hagan, Reynolds, and Smith, 2012). This system focuses on supporting whanau to achieve outcomes and access support in a range of areas (from healthcare, education, social services, etc.). Extending such an indigenous culture-friendly approach to vocational rehabilitation services would enhance uptake and access by ATSI and Maori people in rural and remote settings.

Reflection Learning Exercise

Examine the utility of the construct of cultural safety in the context of provisioning of vocational rehabilitation services to indigenous populations. What would be the key qualities of culturally safe vocational rehabilitation services with indigenous people? How may such services be similar or different from mainstream vocational rehabilitation services?

Strengthening Social and Technological Networks

Developing and improving the social and technological networks of people with disabilities are important objectives that will in most cases have a positive influence on quality of life and social and vocational participation (Craig, Moses, Tran, McIsaac, & Kirkup, 2002; Craig, Nicholson Perry, Guest, Tran, & Middleton, 2015b; Craig, Tran, McIsaac, & Boord, 2005; Guthrie & Harvey, 1994; Murphy, Middleton, Quirk, De Wolf, & Cameron, 2011). Craig et al. (2015b) and Murphy et al. (2011) have shown social support to be significant predictor of social participation in people with severe impairment such as spinal cord injury. Ryan and colleagues (Ryan et al., 2010) showed that social support, in this case, in the form of caregivers' support to the client, strengthened commitment to the goals of those with the disability and was crucial to successful rehabilitation and return to work outcomes.

Likewise, the development and utilisation of assistive technology can result in great benefits, not only psychologically but also in social and vocational participation, as people with disabilities are able to regain lost function through technological assistance (Craig et al., 2005). For instance, eye gaze and voice activation technology have resulted in substantial improvements in capacity to function in the workplace for many people with disabilities, allowing them to be employment competitive (Craig et al., 2005). For individuals with severe disability (e.g. those with no or little arm function), novel interfaces such as eye gaze and brain wave activity have been developed, which provide capacity to control external electrical devices essential for employment readiness (Craig, et al., 2002, 2005). These state-of-the-art technologies are largely unavailable to rural and remote communities adding to their vocational rehabilitation services deprivation.

Other technological innovation that would considerably improve service delivery and rehabilitation vocational outcomes for people with disability in rural and remote settings includes video-teleconferencing communication (Forum, 2006). Video teleconferencing involves technology that allows people to be linked together through wherever they are geographically. The people involved can hear and/or see each other and respond interactively. This type of technology provides assistance for people with disabilities, given the assistive technology controls available (Craig et al., 2005). Teleconferencing in the form of telehealth and tele-rehabilitation is also becoming very important for improving health in people with disability (Agostini, Moja, Banzi, Pistotti, Tonin, Venneri, & Turolla, 2015). These work and employment enabling technologies would readily apply to service and technical trade occupations in rural and remote settings which are linked to parent business hubs in the major urban centres. The evidence for the utilisation of video-conferencing-based technologies in the provisioning of vocational rehabilitation services in the Australia region is yet to be gathered and aggregated.

Research Needs

Research is needed on the personal resourcing of people with disabilities for vocational engagement in rural and remote areas. In this regard, vocational rehabilitation interventions based on supporting motivation, hope and optimism in vocational roles would be important. Research evidence is also needed on the transportability of evidence-based vocational rehabilitation interventions within rural and remote settings, including the cultural-contextual validity of decisions from the vocational rehabilitation assessment being implemented. Furthermore, evidence is needed on vocational rehabilitation interventions that would work with ATSI and Maori peoples in the rural and remote areas and which are designed to assist them to engage in work that they find both meaningful and productive. The efficacy of existing rehabilitation services with cultural minorities in rural and remote Australia cannot be assumed.

Improving Motivation and Optimism/Hope in People with Disabilities

Motivation, optimism and hope are essential personal resources for successful vocational participation with disability (Craig, 2012; Wagner & McMahon, 2004). Evidence is needed on the types of personal resourcing interventions premised on motivation, optimism and hope to enhance the occupational resilience of people with disability in rural and remote settings. The relative isolation of rural living makes it imperative that motivation, hope and optimism are enhanced, leading to robust mental health and eventual successful vocational participation. Furthermore, living with a disability presents with ongoing challenges as the process of adjustment for successful work participation occurs over an extended period of time. The related adjustment process is less well understood and studied in the context of vocational rehabilitation in rural and remote settings. Personal resourcing in terms of motivation, hope and optimism may make a difference to vocational participation in low-resource rural and remote areas.

Developing and trialling strategies for increasing motivation and promoting optimism and hope will therefore be a crucial step in enhancing vocational rehabilitation with people with disabilities in rural and remote settings (Kortte, Stevenson, Hosey, Castillo & Wegener, 2012). For instance, vocational rehabilitation interventions with people with disability premised on boosting the personal resourcing for resilient work participation may include working with the person with disability to adopt "survival mode"-oriented behaviours for full community inclusion (Livneh & Parker, 2005). White, Magin, Attia, Sturm, Carter and Pollack (2012) found stroke survivors with internal locus of control to report lower levels of psychological distress with a higher internal locus of control. Internal locus of control is aligned with personal motivation, hope and optimism.

Optimism and hope build personal resilience by strengthening inner resources that buffer against the impacts of negative life events, with the consequence that the individual comes to expect that their life goals can be achieved despite the barriers (Craig, 2012; Korte et al., 2012), including vocational goals. Traits such as hope and optimism build resilience and facilitate greater psychosocial and vocational engagement (Craig, 2012; Kortte, et al., 2012). Wagner and McMahon (2004) concluded that the person with the disability may be more motivated to participate in the rehabilitation process if the future benefits are made clear. However, a focus on environment contingencies for vocational goal attainment with disability would likely result in greater occupational success than with internal locus of control alone. The conditions under which locus of control as motivational personal resourcing in vocational settings transitions to a healthy balance between external and internal sources are have not been researched, although findings would be important to the design of person and context sensitive vocational rehabilitation interventions in rural and remote regions.

Reliable and Valid Vocational Rehabilitation Service Protocols

Research is also needed on the accurate and sensitive functional assessment of people with disability to optimise vocational success in rural and remote settings. For instance, vocational rehabilitation services within rural and remote communities should also increasingly prioritise work with environmental health departments to proactively address and redress the social impact of industries with significant risk for occupational hazards or those that have the potential to degrade employment opportunities for the residents. Where technology innovations are adopted, these should take into account the relatively lower levels of literacy among rural and remote Australian communities, so as to yield valid data for vocational advising. Cultural community members such as ATSI and Maori people may find technology-based data collection on their vocational rehabilitation needs too impersonal and off-putting, with the result that they may resist using those tools (Steohens, Wargent, Catherall, Timms, Graham, & Clough, 2013). Evidence is needed on technologies that work in providing vocational rehabilitation services in rural and remote Australasia.

Vocational Rehabilitation Models for Rural and Remote Areas

Research is needed on vocational rehabilitation models that would work in rural and remote Australasia. These would need to be informed by the community dwellers utilising participatory action research approaches (Gauld, Smith, & Kendall, 2011). Community-based rehabilitation models (Kuipers, Gauld, Kendall, Smith, & Bowen, 2013) appear to hold high promise with ATSI and Maori people in their use of local resource persons for service access and utilisation. ATSI and Maori liaison counsellors would be a major asset in vocational service provisioning from their intimate knowledge of lived work experiences as indigenous people. The specific roles ATSI and Maori vocational rehabilitation counsellors would engage are in need of research documentation and implementation trialling in remote and rural communities.

Summary

Vocational rehabilitation is a key strategy for increasing employment rates of people with disabilities in Australasia. A number of conclusions follow from research evidence considered in this chapter. Rural and remote country settings present with an occupational ecology characterised by low employment demand levels and restrictions in the availability of rehabilitation services for those who would benefit from such services. Community-driven employment demands will influence work participation opportunities as well as the quality and range of employment support services. In the context of rural and remote Australasia, vocational rehabilitation services for employees in service and farming and farming type of occupations will likely have high levels of demand, as compared to those that may be required for professionals. For service-related occupations in rural and remote Australia, which in essence are similar to those in the urban centres, it may well be that the same proven vocational rehabilitation services used in urban areas might well transport to rural and remote settings. It will also mean that vocational rehabilitation professionals in rural and remote Australian communities increase their understanding, counselling and communication skills to work effectively with farmers and farm employees who may have occupation-related injuries or health conditions that impact their work capacity. With workers in less well-known occupations, in particular, the need would be for vocational rehabilitation professionals to have a solid foundation in identifying and supporting use of transferrable work skills. Furthermore, it is crucial that policymakers and vocation service providers consider the needs of the unemployed and disabled, especially those with mental health problems in rural and remote settings.

The nature of economic activities in rural and remote regions is influenced by the specific area's proximity to urban centres that have established vocational rehabilitation services. The unregulated appropriation of rural and remote community resources by extraction and other external industry with no return of investment to local communities can be a major driver of disability and disadvantage among community members. Future research will be needed to address this significant problem.

Research Review Question

Propose a brief research proposal to investigate a vocational rehabilitation service aspect of choice. Outline the goals of the research and how it might be implemented. Consider the aspects you would build into the design of the study to be translatable into real vocational rehabilitation service provisioning.

In both Australia and New Zealand, vocational rehabilitation services tied to social security policy arrangements are intended as an overall response to disability. Mainstream vocational rehabilitation services may also be poorly aligned with indigenous populations in rural and remote areas of Australasia who have an historical disadvantage, whose rich cultural heritage is generally poorly appreciated. A more holistic and socially networked approach would better suit many ATSI and Māori peoples in addressing their vocational rehabilitation needs. The significance of work role to rural and remote living will likely be sustained even with advances in technology that bridges the physical space divide, and it hoped that technology-enabled work roles will enhance new vocational opportunities for those in rural and remote settings.

Discussion Questions

1. Outline the legislative and policy foundations of rehabilitation in Australasia. How have the legal and policy instruments been assets or impediments to the vocational rehabilitation services in Australasia?
2. Specify the frameworks for the vocational rehabilitation services to rural and remote settings of Australasia. What are their strengths and limitations?
3. Examine any links between vocational rehabilitation services and a unique occupational ecology of rural Australasia. Which of the links make for effective vocational rehabilitation services? Which links could be strengthened and with what potential benefits?
4. Identity and evaluate the feasibility vocational rehabilitation service qualities that would be appropriate for indigenous people of Australasia.
5. Discuss strategies to improve vocational rehabilitation service delivery in rural Australia.

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19

Rural Development, Employment, Chronic Health, and Economic Conditions in Canada

Noel A. Ysasi, Irmo Marini, and Debra A. Harley

Overview

Rural communities in comparison to their urban counterpart struggle to generate revenue to support its economic infrastructure, which contribute to limited access of community resources such as healthcare, childcare, and education and training. These challenges are generally the result of school closures; medical practitioners declining to work in rural communities; lower level of educational attainment; increased aging population, while young adults migrate to urban communities; and a decrease of immigrants taking up residence in rural communities ("Strengthening Rural Canada," n.d.). The latter is demonstrated as immigration increased in urban and metropolitan areas of Ontario by 124% between 2001 and 2011; however, there was only a 2.8% increase within rural populated areas of this region ("Strengthening Rural Canada," n.d.). While it makes sense that people residing in rural communities can access necessary resources by commuting to neighboring urban and metropolitan hubs, approximately six million represent the total rural population, 3.7 million of which live in areas where strong to moderate commuting is possible in comparison to 2.3 million located in remote rural regions (DesMeules et al., 2006). Consequently, many choose to relocate rather than drive great distances, attributing to the decline in rural populated areas and economic prosperity (DesMeules et al., 2006).

The Canadian economy relies heavily upon the exporting of natural resources from rural regions which allow metropolitan and urban areas to prosper; rural communities on the other hand struggle to survive due to a lack of a skilled workforce, declining populations, and the inability to expand and develop economic infrastructure (Moazzami, 2016). However, additional factors directly associated with a declining economy include (a) extreme weather conditions, (b) climate change, (c) lack of transportation of goods, and (d) Aboriginal population affirming their land and treaty rights which inevitably influence industrial development ("Strengthening Rural Canada," n.d.). When an economic infrastructure lacks the necessary resources for its residents, lower perceived quality of life can ensue.

Quality of life can be viewed in terms of good health, increased employment opportunities, job

N.A. Ysasi (✉)
College of Health and Human Services, Rehabilitation Services and Rehabilitation Counseling, Northern Illinois University, DeKalb, IL, USA
e-mail: nysasi@niu.edu

I. Marini
School of Rehabilitation Services & Counseling, University of Texas-Rio Grande Valley, Edinburg, TX, USA

D.A. Harley
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA

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security, and access to community resources. When comparing rural communities with that of their urban counterpart, life expectancy is generally lower in rural areas, mortality rates are higher, and chronic health conditions are more prevalent. The resulting cause is generally due to limited healthcare services (i.e., medical specialists) and hazardous occupations (i.e., mining and farming). Barriers also play a vital role in overall quality of life and have traditionally been a factor for many people with disabilities who reside in rural areas. These often include limited public transportation, poor architectural accessibility, unaffordable housing, lack of social and community support, and reduced employment opportunities for PWDs since many rural jobs are generally more physical in nature. Throughout this chapter, we explore the challenges experienced by Canada's rural regions.

Learning Objectives

By the end of the chapter, the reader should be able to:

1. Understand the demographic characteristics of rural Canada.
2. Understand the economic conditions of rural Canada.
3. Be able to identify the most common occupations, along with the types and size of industry groups in rural Canada.
4. Identify the current health conditions in rural Canada and understand causes for these conditions.
5. Identify strategies for improving service delivery for individuals residing in rural communities.

Introduction

Rural and small towns in Canada is generally made up of diverse communities which continue to play a vital role in the country's economy through the production of food, clean water and air, affording of natural resources to both urban and rural communities, alternative energy, and strong emphasis toward a reduction in carbon emission (Canadian Rural Revitalization Foundation [CRRF], 2015). Socioeconomically, culturally, and environmentally, rural Canada consists of two extremes of the distribution – the most affluent and the most disadvantaged (Alasia, 2004). However, geographically, rural Canada constitutes roughly 95% of its country's landmass and experiences harsh, cold, lengthy winter conditions. Despite these conditions, Canada's largest gross domestic product lies in the areas of forestry, fishing, mining, quarrying of oil and gas (ranked first), and manufacturing (ranked second). A continuing lack of government support, however, is prompting younger rural citizens to relocate to urban hubs for better opportunities (CRRF, 2015).

Since 1851, approximately nine out of ten Canadians lived in rural areas as the economy was primarily driven by agriculture and natural resources (Moazzami, 2016; Statistics Canada [SC], 2015). With a changing global economy and a decline in food production and farming of natural resources, the proportion of people living in rural areas significantly declined between 1921 and 1931, falling below 50% over the last 160 years (SC, 2015). Between 2000 and 2014, the percentage dropped further from 21% to 18%, and among the "Group of Eight" which accounts for eight countries with approximately 50% of the global gross domestic product, Canada falls among the lowest for percentage of people living in rural regions (World Bank, 2014).

Description of Rural Canadian Population

Population size varies significantly among rural regions in Canada and can range anywhere from 14% to 52% of the territories for which they derive. For instance, Quebec (19.4%), Ontario (14.1%), Alberta (16.9%), and British Columbia (14%) are near to or slightly lower than that of the national average with some rural regions with a population at or near one million. Details outlining the urban versus rural population statistics can be found in Table 19.1. Because rural Canada consists of varying demographics based on the

Table 19.1 Population across urban and rural provinces and territories

	Population	Urban	Rural	Urban %	Rural %
Canada	33,476,688	27,147,274	6,329,414	81	19
Newfoundland and Labrador	514,536	305,566	208,970	59	41
Nova Scotia	921,727	521,338	400,389	57	43
New Brunswick	751,171	394,479	356,692	53	48
Quebec	7,903,001	6,368,270	1,534,731	81	19
Ontario	12,851,821	11,045,785	1,806,036	86	14
Manitoba	1,208,268	874,714	333,554	72	28
Saskatchewan	1,033,381	689,983	343,398	67	33
Alberta	3,645,257	3,030,402	614,855	83	17
British Columbia	4,400,057	3,790,694	609,363	86	14
Yukon	33,897	20,562	13,335	61	39
Northwest Territories	73,368	39,938	33,430	54	46
Nunavut	31,906	15,377	16,529	48	52

Source: Statistics Canada (2011)

region of the community and its resources, a review of early adults, aging adults, and Aboriginal people are provided. Specifically, these three groups either impede or aid in the development of rural Canada's economy and comprise the vast number of consumers with disabilities that rehabilitation counseling professionals serve.

Early Adulthood Between 2001 and 2011, urban populated areas increased by 15.13%, while rural regions declined in population by 7.34% (Moazzami, 2016). One of the primary factors for a decline in rural populations has been the result of migrating of youths (29 years of age and younger). For instance, the single most significant factor for a decline in economic conditions within rural communities in Ontario has been the result of 20–30% of youths migrating to urban hubs, particularly Aboriginals who are receiving greater government funding in the cities. Although Canada's government has identified the need for retaining their younger population to improve the current state of the rural economy, many are unhappy with residing in rural communities. This has been attributed to the negative views younger adults have of rural and small towns and the perception that urban living is equated to monetary success, higher social status, and educational opportunities (Malatest, 2002). Malatest found 55% of rural youths indicated they planned on relocating to an urban hub, and for those who currently resided in a urban community, only 37% planned on returning to a rural region. However, the aforementioned factors are not solely the cause for youths migrating to metropolitan and urban communities. Particularly, many rural areas have experienced a significant rate of school closure often necessitating families to either commute or relocate to urban hubs, and access to post-secondary education and trainings is often less accessible in rural regions (Malatest, 2002). For those who remain in rural and small town areas, there is often little choice as a result of decreased finances, caring for aging family members with a chronic illness and/or disability, uncertainty of the future, and maintaining job security.

In another study of outward migration of young people from rural communities, MacBride (2013) found key factors used to make migration decision were influenced by a lack of attention to matters that impact youth. MacBride found the key factors and possible points for action include the need for more relevant guidance for rural youth in high school and, later in life, community development strategies that focus on young adults and increased government attention and consultation on rural youth issues. In exploring strategies for rural youth retention, Lui (2015) found strategies in the county or town were mainly focused on four themes: education and training, career opportunities, youth engagement, and local community development. To strengthen youth retention approaches, Lui proposed five recommendations: (a) establishing a youth council, (b) encouraging collaboration to implement plans for county level programs, (c) connecting with youth in high school and before they leave for post-secondary education, (d) creating short-term job opportunities, and (e) promoting county culture and lifestyle and amenities.

An additional factor impacting rural economies is the educational attainment of this group. Malatest (2002) conducted a study of 1091 young adults between the ages of 20–29 years and found only 22% were attending school. For individuals aged 25 to 29 years, only 11% were attending school on a full-time or part-time basis. According to Gilmore (2010), young adults who do not complete high school are especially vulnerable to unemployment, and when they are employed, they work longer hours for less pay than high school graduates. Furthermore, not completing high school is a risk factor for poverty for young adults (British Columbia Teachers' Federation, 2013). As will be discussed further within the rural workforce section of this chapter, when a community has deficiencies in a qualified and skilled workforce, opportunities for economic prosperity can pass by.

Later Adulthood The senior population consisting of persons aged 65 years and older is vastly outgrowing all other age groups, and by 2026, one in five Canadians (9.8 million) will be 65 years of age or older (Division of Aging and Seniors [DAS], 2002). As of 2008, this group accounted for 15% of the rural population, 13% of urban populations, and 33% of disability rates (Dandy & Bollman, 2008). Women form the majority of Canadian seniors by 56%, and considering women have a greater lifespan than men, 46% of women are widowed in comparison to 12.7% of males (Dandy & Bollman, 2008). Overall, however, the aging population has poorer health and is underserved for healthcare services than that of their urban counterpart while maintaining to play a viable role within rural Canada's workforce (DAS, 2002). Nonetheless, as they continue to outgrow other age groups and with the youth relocating to urban hubs, they are often left with the responsibility to care for older family members while generating a source of income. Subsequently, they experience an array of challenges either through ageism, increased pressure to care for others while needing to care for themselves, and common barriers (i.e., lack of available transportation) associated with rural living. As rural regions are left with a high proportion of older adults, we explore this group in greater detail in proceeding sections of this chapter.

As previously discussed, younger aged adults are migrating to urban communities for better opportunities. Hence, support for seniors is often limited, and as a result, they commonly seek employment or prefer to remain employed to care for themselves and/or other aging family members. More than one person out of five in the labor force of rural areas is aged between 55 and 64 years (Martel & Malenfant, 2006). However, as a result of limited job options in rural regions, low educational attainment, and age, aging adults often work in hazardous occupations (i.e., farming) which increase the probability of injury and/or disability. For individuals who work as farmers (women and men), the economic conditions in the agricultural industry can vary and ultimately affect the age at which one retires from these arduous jobs (Keating, Swindle, & Fletcher, 2011). For those choosing to retire, the aging population in rural communities has rated the retirement income substantially lower than those who retire in urban communities (Keating et al., 2001). Subsequently, the barriers to employment and lack of workplace pensions have created rural poverty for this population. Among nonfarming older men and women, they encounter difficulties when resource industries prefer hiring individuals of predominately younger age and thus experience high rates of unemployment and poverty. As a result of these factors, the overall aging population experiences a 30% unemployment rate and a low annual income of $19,162 (Dandy & Bollman, 2008).

Aboriginals The Aboriginal people represent 4% of the total national population and are growing at a substantially faster rate in comparison to the rest of Canada (Canadian Rural Revitalization Foundation, 2015). Within rural nonmetropolitan adjacent regions, Aboriginal people represent 6% of the population and 34% within rural northern regions and are expected to remain a fundamental factor in rural demography (Bollman, 2007). Aboriginals, also known as Indigenous Canadians, comprise three groups: First Nations (North American Indian), Métis or Inuit, and Treaty Indian or a Registered Indian (O'Donnell & Wallace, 2011). And contingent upon the group, their primary place of residence differs. Approximately 45% of Registered Indians live on the reserve, non-status Indians (75%) and Métis (71%) live in urban areas, and 56% of Inuit reside in rural communities and small towns (Aboriginal Affairs and Northern Development Canada, 2013). In comparison to the national average, Aboriginals have higher poverty rates, mortality rates, suicide rates, lower life expectancy, decreased employment rates, higher percentages of chronic and communicable diseases, and poorer educational opportunities (Assembly of First Nations, 2011). Based on the aforementioned inequalities experienced by the Aboriginal population, they continue to assert their treaty and land rights to improve the quality of life for their people, a primary driver for influencing Canada's rural economic conditions (State of Rural Canada, 2015).

Canadian Rural Economy

Apart from effective counseling (e.g., empathy, unconditional positive regard, good listening skills, etc.) and a collaborative effort between a counselor and consumer, a thorough understanding of the economic conditions of the community for which a rehabilitation counselor operates under is fundamental for successful employment outcomes. As such, we explore the following: (a) occupations and industry groups, (b) size of industry, and (c) the rural workforce.

Occupations and Industry Groups Historically, the economy in rural communities was primarily driven by occupations such as farming, fishing, forestry, and mining; however, they have become a declining source of livelihood for its residents (Bonti-Akomah, Vignola, & Cahoon, 2015). And though Canada's economy continues to rely on agriculture, the gross domestic product (GDP) is only 1.7% (Bonti-Akomah et al., 2015). Nonetheless, they account for 18% of rural professions and contribute to increased disability rates as a result of unsafe working conditions (DesMeules et al., 2006; Rothwell, 2007). Today, the largest sector in nonmetropolitan Canada is social and personal services (i.e., education) and distributive services (i.e., transportation services), followed by producer services, construction, and manufacturing (details outlining the percentage and description of each industry can be found in Table 19.2). More often, people in rural Canada are being employed by small- and medium-sized enterprises (SMEs) (Reimer & Bollman, 2010). Originally, manufacturing accounted for 8.9% of the country's GDP in 2002 but fell to 5% in 2014 due to government programs shifting toward alternative energy (Bonti-Akomah, et al., 2015). But manufacturing is not the only issue in which rural Canadians must contend with as economic restructuring is occurring among all industry groups. Specifically, the changes which have directly affected the economy include:

- Climate change
- Loss of transportation for goods
- Increased flooding and wildfires
- Migration of younger adults to urban communities
- Impact of extreme weather conditions on water quality and infrastructure
- Infestation of pests and diseases to crops (Bonti-Akomah et al., 2015; Warren & Lemmon, 2014)

Industry Size The role and function of vocational rehabilitation counselors (VRCs) extend far beyond general counseling skills; they entail detailed knowledge of the economy as previously discussed and the size of industries that operate within the region for which we provide job placement services. The latter, however, is often dependent upon the areas in which we offer services. For example, it is common knowledge that job opportunities are more prevalent in metropolitan areas; therefore, whether companies employ 200 or more personnel may be of little use to a VRC. Conversely, rural areas are often limited with employment opportunities, and thus, VRCs must be thoroughly versed in all aspects of the economic characteristics of their region. To illustrate this point, let us consider the following demographic statistics. In 2007, 22% of businesses located in rural communities were estimated to have 371 firms for every 10,000 residents in comparison to large urban districts with 331 firms for every 10,000, (Rothwell, 2007). What is of particular importance is the size of the firms which greatly differ from one another. Twenty-percent of businesses in rural sectors generally have 1 to 4 employees, whereas 10% of urban businesses employ 200 or more personnel (Rothwell, 2007). Thus, employment opportunities in rural regions are vastly outnumbered by their urban counterpart which often results in residents choosing to commute and oftentimes relocate to urban centers for work (Moazzami, 2016). With this in mind, we turn our attention to the labor force demographics as rural communities often lack the necessary skilled workers as a result of the aforementioned cause for relocating to urban hubs.

Table 19.2 Rural employment by industry group

Industry group	% of total rural employment
Primary industry (agriculture, forestry, fishing, hunting, mining, oil and gas extraction)	18%
Construction	12%
Manufacturing	5%
Distributive services (wholesale trade, transportation and warehousing, and information and cultural industries)	23%
Producer services (finance and insurance; real estate and rental leasing; professional, scientific, and technical services; management of companies and enterprises; and administrative and support)	15%
Social and personal services (education, healthcare and social assistance, arts, entertainment and recreation, and public administration)	27%

Source: Rothwell (2007)

Rural Workforce In 2006, rural communities in Canada had higher high school dropout rates (16.4%) which were nearly twice the rate of urban communities (9.2%) and had lower percentages of residents with only some post-secondary education; and among the Organisation for Economic Co-operation and Development (OECD) which consists of 35 countries committed to democracy and the market economy, they have the largest and poorest rural-urban gap with regard to education and workforce (Canada Council on Learning, 2006). The importance of a community's workforce is essential to sustainability, yet when a community has deficiencies in a qualified and skilled workforce, opportunities for economic advancement can pass by. For example, Magnusson and Alasia (2004) conducted a study to assess for workforce comparisons between rural and urban communities and found unskilled employment opportunities were predominately found in rural regions in comparison to urban areas where greater proportions of high skilled occupations existed. Hence, low educational attainment and an unskilled workforce inevitably determine the proportion of employment opportunities. Furthermore, with rural communities aspiring to evolve and improve economic conditions in a changing global economy (i.e., technological advances in alternative energy), a society lacking a workforce with qualified skill sets and knowledge will ultimately create barriers and impede rural development. To overcome this challenge, the "integration of new learning technologies into a rural human capital development strategy" is a recommended initiative to enhance a community's workforce (Canadian Rural Revitalization Foundation, 2015, p. 5). However, unless rural regions make significant strides toward the advancement of education and employment opportunities, opting to relocate often becomes the viable choice.

Health Conditions of Rural Canadians

Although Canada with its 33 million plus population enjoys universal healthcare, it has long needed reforms regarding the quality of healthcare provided to its citizens. The Public Health Agency of Canada released a report several years ago on the health conditions of Canadians, noting that approximately 42% of its citizens live with at least one chronic disease. Interestingly, health conditions have been found directly related among native-born citizens versus immigrants (Public Health Agency of Canada [PHAC], 2008). Even when accounting for differences in age, education, and income between these two groups, the incidence of persons acquiring a chronic disease has remained consistent among individuals who are native-born. However, for those who have immigrated and lived in Canada for 30 or more years, the incidence for chronic diseases remains relatively consistent with that of their native-born counterpart (PHAC, 2008). These chronic diseases include the following:

- Asthma
- Arthritis
- High blood pressure
- Diabetes
- Heart disease
- Stroke
- Pulmonary disease
- Cancer
- Crohn's disease
- Thyroid condition
- Eating disorders
- Glaucoma
- Colitis
- Epilepsy
- Alzheimer's
- Schizophrenia
- Mood disorders
- Anxiety disorders

Aging citizens of rural populated regions experience an even higher incidence of chronic health conditions. The Division of Aging and Seniors (2002) conducted a study to assess for medical conditions among Canadian seniors. Results revealed 52% of respondents perceived their health to be favorable which ranged from good (12%), very good (28%), and excellent (12%); however, more than 80% had a chronic medical condition. These conditions included (a) arthritis and rheumatism, (b) high blood pressure, (c) allergies, (d) back problems, (e) chronic heart problems, (f) cataracts, and (g) diabetes. Furthermore, 21% had a chronic disability as a result of falls or labor-intensive employment injuries. Such injuries were also reported a key concern among older adults with women 60% more likely to sustain an injury than men, with the primary cause being a fall.

In Canada, access to healthcare reflects the strong social value of equality (i.e., "distribution of services to those in need for the common good and health of all residents"); however, people residing in rural and remote areas do not experience such equality (Browne, n.d., p. 1). According to Browne, major factors that contribute to inequities in access to health services of resident living in rural and remote regions of Canada include geographic barriers, limited availability of healthcare personnel and services, hospital downsizing, and cultural differences. In response to the challenges facing healthcare delivery in rural areas, rural-oriented education programs and clinical experience for medical and nursing students are recognized as an effective means of training and retaining graduates in rural areas. In addition, telehealth has the potential to improve both the health and the healthcare of people living in rural Canada (Herbert, 2007).

To assess for health disparities between urban, metropolitan, and rural populated areas, Shields and Tremblay (2002) found metropolitan areas had increasingly higher positive health outcomes in comparison to rural communities. Canada's largest cities (Toronto, Montreal, and Vancouver) and those with populations exceeding 500,000 tended to be among the healthiest in the country as smoking, drinking rates, and obesity were lower than the national average and rural populated areas. Moreover, increased life expectancy is favorable in urban and metropolitan areas. For example, Richmond, British Columbia's average life expectancy is 81.5 years. Conversely, socioeconomic conditions among rural Canadians (e.g., lower educational attainment and low income) were found to be positively correlated to unhealthy living (DesMeules et al., 2006). Similarly, geographically rural remote regions with significantly greater distances to urban or metropolitan areas have the lowest life expectancy and highest rates of smoking, drinking, and obesity in the country. Aboriginal Canadians living in the remote North have particularly higher rates of these conditions substance abuse and suicide.

Determinants of Chronic Health Conditions and Disability

Determinants of rural health have been directly linked to hazardous occupations such as fishing, mining, farming, forestry, and meatpacking industries. These occupations contribute to high accident rates, work-related diseases, and early retirement (Laurent, 2002). Although work conditions for miners have improved considerably, exposure to silica and radiation has resulted in silicosis and lung cancer (Shields & Tremblay, 2002). Unfortunately, mining conditions also contribute to obstructive pulmonary diseases and cancer of the bowel, stomach, bone, bladder, and pancreas (Laurent, 2002).

Within the farming/agriculture industry, standard day-to-day operations are often facilitated through the owner (i.e., self-employed farmer), and as such, lack of health and safety regulations is not enforced and thus exacerbates chronic health conditions (Pong, 2002). Pong lists the following as contributing factors of injuries, deaths, and farming-related diseases: (a) farmers tend to work in isolation; (b) average farm size has increased four times over the last 20 years resulting in longer distances to local services and neighbors; (c) children and older adults are often present at worksite; (d) farmers are exposed to harmful chemicals; and (e) farmers experience high levels of stress due to the competitive global market. Kubik and Moore (2005), for example, found that 57% of woman farmworkers felt sad or depressed, had trouble relaxing, and felt anxious and 67% reported difficulty in sleeping; financial problems accounted for 45% of the stress experienced followed by harvest and seeding (17%), extensive work (9.5%), harsh weather conditions (5.2%), uncertainty (4.9%), and family disagreements (4.3%).

Another cause for concern among residents and local governing officials involves an insufficient healthcare workforce (Pong, 2002). The rate of medical practitioners choosing to work in Canada's rural areas continues to be problematic and in need of stronger efforts in recruitment and retention. The University of Ottawa, for example, during one time period produced 50 medical doctors; however, only 6 or 12% chose to practice in rural areas (Laurent, 2002). Key determining factors for declining to work in these communities included social isolation, decreased pay, and longer hours with less support (Laurent, 2002). When a community is unable to meet the healthcare needs of its residents, poorer health outcomes are likely to ensue. As a case in point, when residents are required to commute 75 miles or more to see a physician, they often miss appointments or choose not to seek medical care. With chronic health conditions, injuries, and disabilities affecting this population, support services are critical for improved quality of life. Nonetheless, demographics (i.e., isolated from community resources), depletion of natural resources, high unemployment, the aging population, poor economic development, and inadequate municipal infrastructure are all factors which contribute to the health and well-being of rural Canadians (Cruise & Griffiths, 1999).

Disability and Perceived Barriers Within rural communities, various factors prohibit people with disabilities (PWDs) from living more fully and independently within all aspects of their lives. These are frequently the result of unmet healthcare needs (i.e., long distances to a medical facility or lack of medical specialists), decreased employment opportunities, inability to engage in social activities (often the result of lack of transportation), architectural barriers, and discrimination. For example, Gallagher, Menec, and Keefe (2006) found adults aged 65 years and older living in rural communities reported vast barriers to transportation, accessibility, and lack of social participation opportunities, felt isolated and disrespected (i.e., ageism), were short of support services to foster independence, and lacked awareness of existing programs (i.e., government assistance). @These factors ultimately reduce quality of life and continue the existence of poor health among older rural adults. Details outlining perceived barriers among this population are provided in Table 19.3.

Similarly, Veltman, Stewart, Tardif, and Branigan (2001) found 38.8% of individuals with disabilities had difficulties keeping a medical appointment due to lack of transportation services, 32.3% were unable to access their doctor's office, 38.3% were unable to access the medical equipment during their doctor's visit, and 22.9% could not gain access to a washroom. Surprisingly however, the research was not conducted in a rural region set in Canada but rather the largest metropolitan area, Toronto. As discussed throughout the text, rural and urban areas remain vastly different with barriers most commonly occurring within rural and small town communities. For instance, lack of transportation, employment opportunities, community support and health services, housing, architectural accessibility, and communication and information are barriers affecting all PWDs toward living fully integrated and independent lives.

Table 19.3 Aging population in rural Canada and perceived barriers

Theme	Barriers
Outdoor spaces and buildings	Poor accessibility to and within public buildings (i.e., wheelchair ramps); poor quality sidewalks, curbs, and crosswalks; lack of accessible washrooms
Transportation	Lack of transportation (no buses or taxis); increased expense to travel outside of community; lack of accessibility; and lack of information about transportation options
Housing	Unaffordable; inaccessible housing (i.e., narrow hallways); and shortage of assisted living facilities
Respect and social inclusion	Ageism; abuse; and mobility- or health-related issues leading to isolation
Communication and information	Lack of awareness of existing programs; difficulty toward finding access to government programs; vision- and hearing-related difficulties; outdated information about events; and poor access to cable, radio, or broadband services
Employment opportunities	Transportation challenges and lack of opportunity for and/or barriers to paid employment
Community support and health services	Lack of healthcare professionals; insufficient home care services; high cost home modifications for those with disabilities; and difficulty traveling long distances for medical appointments

Source: Gallagher, Menec, and Keefe (2006)

Implications for Rehabilitation Counselors

When providing services for people with disabilities (PWDs), several considerations must be implemented for a collaborative and meaningful relationship to occur. For instance, as this group identified transportation as a common barrier, they become limited toward seeking employment opportunities and making general appointments with healthcare professionals. Consequently, if a rehabilitation counselor operates within an urban community which borders a rural town, commuting may be a preferred option to hurdle the challenge of obtaining transportation means by the client. Additional recommendations include (a) offering educational services to improve health, well-being, and independence, (b) facilitating inclusion of older adults in social activities to promote independence and enhance quality of life, and (c) strengthening supportive environments within rural communities (DAS, 2002).

Counselors should also not assume that since Canada has universal healthcare, all their clients' healthcare needs are being met. One of the commonly noted problems with universal healthcare is that there is often a long waiting period for diagnostic and operative procedures. Unless one's health condition is life-threatening, many Canadians often have waiting periods of months or years depending on where they reside. These difficulties are compounded for rural residents.

Rehabilitation counselors are also faced with the extremely difficult task of finding employment for PWDs who live in rural settings. Although the vast majority of Canadian citizens live within 100 miles of the American border and reside in urban areas with the requisite services of any major city, those with disabilities in rural areas and especially the Aboriginal population face numerous barriers as noted earlier. Travel to urban centers for social services and medical care during what typically is 6 or 7 months of winter and severe climate conditions is often prohibitive for those with chronic illness and disability to make the journey. Employment opportunities in these areas are not only scarce, but the jobs themselves are most often physically laborious ones that most with disabilities are unable to perform. Those younger individuals with disabilities often migrate to larger cities for the more highly skilled jobs. Aboriginals who choose to move to urban areas are also often faced with discrimination from Caucasians who perceive Aboriginals to be freeloading off government money (Irmo Marini, personal communication September 14, 2016). When working with Aboriginals on employment issues, rehabilitation counselors must be both aware of and acknowledge this discrimination exists and advocate on behalf of Aboriginals to ensure social justice and their human rights are met.

Summary

Although Canada ranks 12 of 201 (US ranks 39 in comparison) in life expectancy rates (World Population Prospects, 2015) and enjoys universal healthcare, it is not without its problems for Canadians with disabilities and those living in rural areas. The harsh winter conditions and limited or no quality healthcare in many parts of rural Canada often leave those with disabilities vulnerable and left to their own devices. Many choose to go without needed healthcare and ultimately become more ill and succumb to a higher mortality rate. Rehabilitation counselors in Canada must think outside the box as far as assisting rural Canadians with disabilities in obtaining adequate healthcare and in their employment efforts, particularly Aboriginals who may also endure even more discrimination. Rural dwellers in most modern societies face isolation, higher incidence of suicide, depression, stigma toward seeking mental health treatment, substance abuse, poorer healthcare, and chronic health conditions (Smith, Thorngren, & Christopher, 2016). Availability and accessibility to healthcare, social services, and related services are often the greatest barriers for rural residents to obtain treatment.

Learning Exercises
Self-Check Questions

1. What are the economic challenges in rural and remote regions of Canada?
2. What are the barriers of the aging population in rural Canada?
3. What types of chronic health conditions consistently affect both native-born and immigrants who have lived in Canada for at least several decades?

Experiential Exercises

Review the case studies below. As a rehabilitation counselor, respond to the accompanying questions.

Case Study One

John Casey is a 56-year-old Caucasian male and retired farmer in northern Saskatchewan, approximately 300 miles from the nearest urban hospital in Saskatoon. Mr. Casey had to retire due to arthritic conditions, but has found being at home doing nothing has made him depressed and looking for part-time work. Since retiring, Mr. Casey has also started to drink too much, and his wife of 27 years is thinking about leaving him. Mr. Casey resides within the rural town of Southend, home to a majority of the Peter Ballantyne Cree nation people which occupy much of the lands in northern Saskatchewan. With a population of 900, two convenience store gas stations, and no health clinic, receiving essentials for daily living can be problematic. Although obtaining food and essentials for the town is largely delivered by transport trucks during the summer months, the winter months make this more difficult, and essential goods must be flown in. Once every 3 months, a convoy of a family practitioner, nurse practitioner, mental health counselor, social worker, and rehabilitation counselor are flown out for 3-day visits to service the community. Interdisciplinary staffing between the five disciplines regarding the rural residents occurs during this time.

Mr. Casey is unwilling to admit to an alcohol problem and does not want counseling, and the team concedes that perhaps involving him in some type of work may be beneficial in minimizing his lethargy and drinking. Mr. Casey is given 6 months of arthritic prescriptions for his flare-ups, and the rehabilitation counselor works within the confines of this small town to assist in obtaining part-time employment for him.

Questions:

1. Discuss what viable options you can pursue to assist Mr. Casey in this effort.
2. What cultural issues should you address?
3. How best can the healthcare and service providers coordinate services in response to Mr. Casey?

Case Study Two

Virgil Rountree is a 23-year-old Aboriginal member of the Kainai Nation reserve, the largest in Canada, southwest to the city of Lethbridge with a population of 83,000. He has a below-the-knee amputation from a farming accident when he was 15, but is able to ambulate very well with the use of a prosthesis. Virgil initially left the reserve after completing his GED at age 20 and going to Red Crow Community College in Lethbridge to obtain a social worker diploma specializing in Aboriginal support care. Virgil was ostracized by some friends and family for leaving the reserve who called him an "apple," and the initial transition left Virgil feeling rejected, isolated, and depressed. He was nevertheless able to obtain his diploma and return back to the reserve where he wanted to help his people whose youth have a high incidence of substance abuse, chronic unemployment, and suicide. Unfortunately, the three social worker positions at the small clinic on the reserve are filled by young social workers who have plans to stay. Virgil has come back to Lethbridge to meet with a rehabilitation counselor in order to assist him with his feelings of loneliness and isolation and rejection from significant others and ultimately to help him find work in Lethbridge.

Questions:

1. What areas do you foresee assisting him within obtaining his goals?
2. What cultural issues should you address?
3. Develop an Individual Plan of Employment for Mr. Rountree.

Multiple-Choice Questions

1. The Canadian economy relies heavily upon exporting which of the following from rural areas to support metropolitan regions?
   (a) Indigenous craft
   (b) Natural resources
   (c) Cultural assets
   (d) Educational attainment
2. Which of the following best describes experiences of individuals with disabilities in seeking medical care?
   (a) Lack of transportation
   (b) Unable to access their doctor's office
   (c) Unable to access medical equipment during their doctor's visit
   (d) All of the above
   (e) None of the above

3. Which of the following best describes a comparison of rural and urban health outcomes?
    (a) Urban dwellers have higher obesity rates
    (b) Rural dwellers have lower drinking and smoking rates
    (c) Urban dwellers have lower drinking and smoking rates
    (d) Urban and rural dwellers are essentially the same for smoking, drinking, and obesity rates
4. Which of the following inevitably determine the proportion of employment opportunities in rural Canada?
    (a) Low educational attainment and unskilled workforce
    (b) Unskilled workforce and availability of natural resources
    (c) Technological advances and natural resources
    (d) Healthcare and low educational attainment
5. Which of the following groups is known as indigenous Canadians?
    (a) Alaskan Natives
    (b) British Columbians
    (c) Aboriginal People
    (d) French Canadians
6. Which of the following groups has the highest level of unemployment and poverty in rural Canada?
    (a) Youth
    (b) Young adults with children
    (c) Farming older men and women
    (d) Nonfarming older men and women
7. Which of the following are directly associated with a declining economy in rural Canada?
    (a) Extreme weather conditions and climate change
    (b) Increasing immigration
    (c) Lower life expectancy and chronic health conditions
    (d) Increasing number of people with disabilities
8. Communities in rural areas and small towns in Canada are considered to be which of the following?
    (a) Less diverse
    (b) More diverse
    (c) Same as urban areas
    (d) None of the above
9. Which of the following is representative of Canada's landmass?
    (a) 60% rural
    (b) 75% rural
    (c) 80% rural
    (d) 95% rural
10. Which of the following is most prohibitive of travel for people with disabilities and chronic conditions to urban centers for social services and medical treatment?
    (a) Inconsistent transit schedule
    (b) Long winters and severe climate
    (c) Inaccessible buses
    (d) Restrictions on federal transportation funding

Key

1 – B
2 – D
3 – C
4 – A
5 – C
6 – D
7 – A
8 – B
9 – D
10 – B

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People with Disabilities and Mental Health Disorders in Mexico: Rights and Practices

20

Debra A. Harley

Overview

Mexico is located in a region of the world (i.e., Latin America) with the highest level of socioeconomic inequality (UNU-WIDER, 2014). The progression of disability is linked to socioeconomic conditions, particularly poverty, in a reciprocal cycle (Diaz-Venegas, Reistetter, & Wong, 2016). Mexican migrants leave economically depressed rural areas and go to urban areas in Mexico, leaving severe poverty in rural areas (Guarnaccia, Martinez, & Acosta, 2005). In 2006, Mexico was one of the 96 countries to ratify the United Nations Convention on the Rights of Persons with Disabilities; however, the Mexican regulations for people with mental disorders have not changed with the reforms. Legislative changes have been made to procedural codes with regard to specific supports that must be implemented for persons with sensory disabilities (Puente & Benavides, 2013). Although strategies for mental health programs have been developed, large-scale implementation is hampered by the lack of specialized human resources and the general budget restrictions on healthcare initiatives (Gonzalez & Alvarez, 2016). See Table 20.1 for timeline of disability legislation in Mexico. According to Jacoby (2016), Mexico's "mental health system is so dysfunctional that the unlucky patients under its care are colloquially referred to as 'abandanodos' – abandoned ones." Disabled World (2015) described the legal status of disability rights in Mexico as contradictory.

In a comparison between General Law for the Inclusion of People with Disabilities, which mandates the state to promote, protect, and guarantee the use of all human rights and liberties of people with disabilities, ensuring the full inclusion into society with respect, equality, and equal opportunities (Consejo Nacional Para las Personas con Discapacidad [CONADIS], 2011) in Mexico, and the Americans with Disabilities Act (ADA), Armendariz and Saladin (2012) assert with the Mexican law being passed in May of 2011 there is not enough information that provides criticism to the effectiveness of the law and how it has impacted its citizen. Conversely, others (i.e., Disabled World, Disability Rights International [DRI], O'Neill Institute for National and Global Health Law) presented evidence to the contrary. Although Mexico has legislation and international agreements in place to ensure the inclusion and nondiscrimination of people with disabilities, the language in those documents is vague and goes mostly unenforced (Russell, 2016). In January of 2017, DRI and the O'Neill Institute for National and Global Health Law filed a case with the Inter-American Commission on Human Rights

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D.A. Harley (✉)
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: dharl00@email.uky.edu

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(IACHR) for the egregious human rights violations against 37 persons with disabilities who were detained at the "Casa Esperanza" institution in Mexico City, Mexico. The case was modeled on the US Supreme Court Case of *Olmstead v. LC* (527 U.S. 581). The decision in *Olmstead* requires all states to provide appropriate services and supports in the community so that children and adults with disabilities are not unnecessarily institutionalized in order to receive services and can live as equal members in the community (Consortium for Citizens with Disabilities, 2013). The case against Casa Esperanza "seeks recognition under the international law that all people with disabilities have the right to live in the community" (O'Neill Institute for National & Global Health Law, 2017, p.1).

Table 20.1 Timeline of disability legislation

1984 – The General Law of Health is revised to include provisions concerning disability
1986 – National Social Security laws are promulgated, granting the rights of social assistance to people with disabilities.
1991 – The General Assembly adopts principles for the protection of persons with mental illness
1993 – The General Law of Education is revised to include provisions concerning inclusion of disability
1994 – Other laws are revised for inclusion of disability: the Stimulus Bill and Promotion of Sports, the General of Human Settlements, and the Law of Public Federal Administration
1999 – The House of Deputies approves legislation reform in favor of persons with disabilities having full access to healthcare rights
2005 – National disability law is signed by congress, General Act on the Inclusion of Persons with Disabilities
2007 – The United Nations Convention on the Rights of Persons with Disabilities (CRPD) signed and ratified
2011 – National disability law is signed and ratified, General Act on the Inclusion of Persons with Disabilities
2014 – Concluding recommendations for the CRPD Committee published

Adapted from Global Disability Rights Now (n.d.)

Contextually, it is important to know historical events in Mexico that lead to the passing of the law and to understand the Mexican disability background (Armendariz & Saladin, 2012). Nevertheless, awareness of disability rights in Mexico is low for both people with and without disabilities (Disabled World, 2015) and for children and adults (Consortium for Citizens with Disabilities, 2013). The most recent assessment is that Mexico authorities fail to protect children and adults with disabilities. In Mexico, "mental health is recognized as one of the main unresolved issues within the government's health policy agenda" (Gonzalez & Alvarez, 2016, p. 2).

Learning Objectives

Upon completion of this chapter, the reader will be able to:

1. Understand Mexican beliefs about wellness and healthcare practices.
2. Understand social exclusion and the rights of people with disabilities.
3. Identify challenges of persons with mental disabilities in the Mexican criminal justice system.
4. Identify barriers to service delivery and treatment.
5. Consider strategies to improve service deliver for people with disabilities.

Introduction

Mexico (the United Mexican States) is a federal constitutional republic in North America that is bordered on the north by the USA; on the south and west by the Pacific Ocean; on the southeast by Guatemala, Belize, and the Caribbean Sea; and on the east by the Gulf of Mexico. It is the fifth largest country in the Americas and the most populous Hispanophone (Spanish-speaking) country on earth (Disabled World, 2015). Mexicans have a unique culture of their own, speak a variety of languages and dialects and have different communication styles, vary in the acculturation process, and have gender role and generational expectations and cultural practices. The Mexican government estimates there are over 12 million indigenous people in Mexico coming from diverse cultures and speaking 62 officially recognized languages (Instituto Nacional de Estadistica Geographica e Informatica, 2007).

Overwhelmingly, Mexicans are Roman Catholic, followed by Protestantism. A small percentage of Mexicans adhere to *spiritism* (belief in God and spirits, Allan Kardec, the codifier of spiritism) in which they are supported and enriched through prayer and belief (Kardec, 2007). Religion and faith are considered important to the maintenance of health and well-being (Ortiz, Shields, Clauson, & Clay, 2007).

Family is another vital part of Mexican culture and is actively involved in health practices and healthcare-seeking behaviors of family members. Mexican families are traditionally large, and it is not uncommon for multiple generations to live in the same household. There is extensive family involvement and much emphasis is placed on helping one another in day-to-day life. Both status and opportunities of individuals are strongly influenced by family ties across the lifespan (Willey et al., 2017). Mexicans value inclusion of all family members. Although Mexican families tend to be patriarchal and follow a rigid hierarchical structure and women are expected to manifest respect and even submission to their husband, privately it is some women (the mother) who holds a greater degree of power and plays a pivotal role in healthcare decisions (Medina, n.d.). Many Mexican women assert their influence indirectly, thus preserving the appearance of male control (Durand, 2011). It is important to understand that while Mexicans share common attributes, beliefs, and norms, they are not homogeneous but have a distinct culturally hybrid characteristic because of the influence of Spanish colonization and native culture.

The daily lives of people of Mexico vary dramatically according to socioeconomic status, educational level, gender, ethnicity and racial perceptions, regional characteristics, rural versus urban differences (Willey et al., 2017), and disability. Rural poverty is widespread due largely to an increasing proportion of rural residents that do not own land and depend on day labor, which pays less than minimum wages. Similarly, the majority of urban dwellers have incomes below the poverty level (Willey et al., 2017). People with disabilities are overrepresented among the poor, especially for older adults (Comision Economica Para America Larina Y El Caribe (ECLAC, 2012; Laurin-Bowie, 2004). According to the ECLAC (2012), both emotional and financial responsibility of care for people with disabilities fall on the immediate family because significant shortfall exists in care services provided by the state, the market, and civil society organizations. Laurin-Bowie asserts "poverty, in itself, is an effect. It exists due to the concentration of a number of factors" (p. 21). These causes are structural (social, political, economic, and dominant cultural structures that have developed over time), current (social factors and phenomena that worsen the conditions of poverty), and external ("streams of thought and action outside of the country that influence the particular conditions in a determinate way, and are combined in order to increase the social gap, and consequently the incidence of poverty," p. 22).

Cultural Beliefs About Wellness/Illness and Mental Health

In keeping with Mexican practice, discussion of psychiatric disorders or mental illness and somatic diseases is not dichotomized. Mexicans have distinctive beliefs about wellness/illness. In traditional Mexican culture, it is believed that illness results from three causes: sin, imbalance, and witchcraft (Cartwright & Shingles, 2011). Life is about balance, and imbalance may make a person sick. The mind-body-soul must be in balance in order to maintain wellness. A mental or emotional imbalance (illness) may cause physical imbalance (illness) because of too much stress. Thus, each person is responsible for maintaining his or her balance (Cartwright & Shingles). *Curanderismo* greatly influences the beliefs of Mexicans regarding illness and mental health. *Curanderismo* is a mind-body-spirit healing approach steeped in tradition and ceremony. Religious beliefs greatly influence wellness practices. Mexicans have a strong belief that life is in God's hands (Spector, 2017). In Mexican culture the belief of health and illness is based on the thought that physical and mental illness is God's way of conveying unhappiness with a person

(Cartwright & Shingles). Good health means one is being rewarded from God for good behavior. Mexicans may take a seemingly passive approach to addressing illness and resign themselves to the influence of fate (*fatalismo*). This approach is grounded in an external locus of control.

A third belief is that illness can result from an imbalance of hot and cold and wet and dry properties (Giger, 2017). Hot and cold do not strictly refer to temperature but refer to the cultural classification of a particular substance or illness. "Hot" illnesses should be treated with "cold" remedies. "For example, penicillin, which is classified as a 'hot' medication, should not be used in treating 'hot' symptoms such as rashes. Another view of the role of 'hot' and 'cold' balance in illness is that the cold should be avoided after having an extremely hot experience. For example, after doing extensive ironing in the house, a person should avoid stepping directly into the outside air in order to avoid becoming sick" (Spector, 2017, p. 220). This belief is tied to the four body humors (blood, yellow bile, phlegm, and black bile). An imbalance in the humors is believed to cause either physical or emotional illness (Cartwright & Shingles). Clearly, illness is viewed as a discord between elements of balance or as a punishment.

Witchcraft and superstition are highly integrated into Mexican culture and healthcare beliefs and practices (Sparks, 2009). Some beliefs in Mexican culture of the cause of illness include the "evil eye" (*mal de ojo*, belief that someone with evil powers or thoughts can cause you to get sick just by giving the person the evil eye), fright (*susto*), shock (*espanto*), and bad air caused by exposure to drafts (*mal aire*) (Berger, 2012). Another belief is envy (*envidia*) which may cause illness when a person experiences success. The belief is that one should keep quite about his or her success because others may envy him or her, thus resulting in illness due to good fortune (Spector, 2017).

Curanderismo is defined as a medical system. The *curandero* (shaman) is a holistic healer, and the people seek help from him for social, physical, and psychological purposes (Sparks, 2009). Curanderismo has historical roots combined with Aztec, Spanish, European witchcraft, Greek humoral (equilibrium of hot and cold), spiritualism and psychic, homeopathic, African (*Santeria* blend of Catholic saints and African *Orishas*), Judeo-Christian (gift from God and belief in God), and scientific elements (Torres, 2005). Often, traditional family or folk medicine has priority over Western medicine.

In Mexico, cultural stigma is associated with mental illness, which results in reluctance to seek treatment. The term *loco* is often used when Mexicans think of mental illness. In addition, *machismo* (manliness) also can be a barrier to male seeking treatment. Machismo means that the husband is the protector, provider, and the decision-maker for the family. Often, the concept of *machismo* is used in popular press as a stereotype to describe Mexican males as having an exaggerated sense, and it has also become distorted by many Mexican males who abuse their power within the family (Medina, n.d.). Unfortunately, the concept of *machismo* is seen as an assumptive attitude of strength and entitlement to dominate as attributes of masculinity (Dictionary.com, 2017). In addition, the gender role of *marianismo* serves both to idealize women in some respects and oppress them in others.

Cultural beliefs and practices can be both a motivator for and a barrier against accessing and following through with services. Because of the unique cultures of Mexicans, it is important to understand the contextualization of their beliefs if progress is to be made in reducing and/or eliminating the disparities found in the availability, access, and provision of mental health service delivery. Acosta (2008) offers guidelines on do's and don'ts when working with Hispanic in mental health (see http://www.nrchmh.org/attachments/DoAndDont.pdf).

Prevalence of Disabilities and Mental Health Disorders

Estimating the prevalence of disability in Mexico is difficult for several reasons: (a) each country uses different measuring instruments with variations in questions, (b) the use or nonuse of a priory definition of disability, (c) lack of a common language, (d) surveys with limited focus and domain coverage looking mostly at few impairments, and (d) limited linkage with health surveys (Soliz, 2005). Often, these reasons lead to underestimation of the number of people with disabilities. However, data do exist that provide some context of disability in Mexico. Furthermore, it is suggested worldwide and in Mexico the number of people with disabilities is increasing due to the rise of chronic diseases, injuries, violence, automobile accidents, and other causes such as aging (Soliz). In Mexico, mental disorders have been shown to increase the risk of other diseases and are strongly associated with the prevalence of chronic diseases. In addition, individuals with chronic diseases are more prone to experience depression or other mental health disorders. Furthermore, depressive disorders in Mexico create a comparable disease impact to that of interpersonal violence, road injuries, or congenital anomalies and a greater impact than that of cerebrovascular disease, HIV/AIDS, or some types of cancer (Gonzalez & Alvarez, 2016).

According to the Diario Oficial De La Federacion (2014), in Mexico, 7.5% (9.17 million) of the population has a disability, of which 45.33% (4.16 million) are mobility related, 26.01% (2.39 million) are visual, 16.13% (1.48 million) are cognitive, 15.70% (1.44 million) are auditory, 4.87% (0.45 million) are speech, and 23.5% (0.10 million) are others. A larger percentage (27.4%, 2.41 million) of people with disabilities live in rural areas versus 26.4 million (21.6%) live in urban areas. More males (53%, 4.86 million) than females (47%, 4.31 million) have a disability. In comparison to the total population receiving a secondary education 78.3% (95.76 million), only 15% (1.38 million) of people with a disability are receiving a secondary education. The employment rate for people with disabilities is 47.2% (4.33 million) in comparison with the total population (60.1%, 73.50 million). A substantially higher percentage of people with disabilities (45%, 4.13 million) live in poverty compared to the total population (11.3%, 13.82 million). The rate of disability increases with age, with the highest rate among adults age 60 and over (51.4%, 4.71 million). Rates of occurrence of disability among other age groups are (a) ages 0–14 at 7.3% (0.62 million), (b) ages 15–29 at 7.6% (0.70 million), and (c) ages 30–59 at 33.7% (3.09 million) (Diario Oficial De La Federacion, 2014).

Medina-Mora et al. (2005) assert while psychiatric disorders are common (12-month prevalence of 12.1%), very severe mental disorders are less common (3.7%) in Mexico. In addition, extreme underutilization of mental health services exists, with only 24% of individuals more severely affected using any services at all. The most commonly identified disorders included specific phobia (4.0%), major depression (3.7%), and alcohol abuse (2.2%; Medina-Mora et al., 2005). Severity of illness was correlated with income, with people with low incomes more likely to report a disorder. Females were more likely to report a mood and anxiety disorder and less likely to report a substance abuse disorder (Medina-Mora et al.). In a subsequent study, Medina-Mora, Borges, Benet, Lara, and Berglund (2007) found of those surveyed, 26.1% had experienced at least one psychiatric disorder in their life and 36.4% of Mexicans will eventually experience one of these disorders. Moreover, half of the population with a psychiatric disorder present so by the age of 21 and younger cohorts are at greater risk for most disorders.

The prevalence of intellectual and developmental disabilities (I/DD) is even more difficult to gage than other types of disabilities because psychiatric hospitals for the adult population neither refer to nor quantify intellectual disability as a primary diagnosis. In addition, population surveys of psychiatric disorders often use the Composite International Diagnostic Interview (CIDI), which does not include a validated questionnaire of I/DD. Furthermore, mental health professionals in Mexico either underreport or misclassify intellectual disability (Katz, Marquez-Caraveo, & Lazcano-Ponce (2010). Despite the difficulty to determine the magnitude of intellectual disability, Lazcano-Ponce, Rangel-Eudave, and Katz (2008) estimate a prevalence rate of about 3% (3 million). According to

Emerson (2007), failure to include or the social exclusion of people with intellectual disability is directly proportional to the degree of poverty and conceptually related to three components: (a) economic deprivation (insufficient family income, inadequate job training, and a lack of job opportunities for this population), (b) social deprivation (families segregate people with I/DD from the community where the likelihood of disruption of social and family ties is greater in this population), and (c) the absence of political representation and, subsequently, of social empowerment (the lack of participation in decisions that affect their daily life).

Diaz-Venegas et al. (2016) explored the progression of disability in Mexico by implementing a model to examine how this process compares to the USA, with a focus on gender differences. The USA and Mexico exhibit different epidemiological, socioeconomic, and health characteristics that not only expose individuals to specific living conditions but put them at risk of acquiring a disability in old age. A proposed model for disablement is one that progresses from no limitations to one limitation (only in mobility), to two limitations (in mobility and limitations in instrumental activities of daily living [IADLs] or activities of daily living [ADLs]), to three limitations (in mobility, ADLs, and IADLs), and finally to death. The goal is to establish the order in which the combination of disabilities will be present in a population of healthy adults (see Research Box 20.1).

Research Box 20.1

See Diaz-Venegas et al. (2016).

Objective: This study seeks to document the progression of disability in a developing country by implementing a model to examine how this process compares to a developed country.

Method: Data were analyzed from the Mexican Health and Aging Study (MHAS), including a baseline survey in 2001 and a follow-up in 2003, and from the US Health and Retirement Study (HRS), using 2000 and 2002 waves. An ordinal logistic regression approach is used to examine a progression of disability that considers (a) no disability, (b) mobility problems, (c) mobility plus limitations with IADLs, (d) mobility plus limitations with ADLs, (e) limitations in all three areas, and (f) death.

Results: In both data sets, approximately 44% of the sample remained in the same level of disability at the 2-year follow-up. However, the progression of limitations with two disabilities differs by gender in the MHAS but is consistent for both men and women in the HRS.

Conclusion: One model reflects the importance of ADLs in the disablement process in Mexico. We speculate that the difference in lifetime risk profiles and cultural context might be responsible for the divergence in the progression of disability by gender.

Questions

1. Were the sampling frames comparable in this study?
2. What other type of methodology might have been used in this study?
3. What implication does this study have for planning collaboration in disability service delivery between Mexico and the USA?

Ethnic and Ethnopharmacology

Ethnic pharmacology refers to the correlation between race/ethnicity and how a person's body metabolizes medications. Although "ethnopharmacology deals with how physiological and genetic differences between racial and ethnic groups impact the effectiveness of pharmacological products, it also looks at how people's cultural beliefs about their health have an impact on the medications they use, how they use them, as well as how racial bias and cultural attitudes affect the development and prescribing of certain drugs" (Minority Nurse, 2013). Understanding the effects of medication on ethnic minorities in the treatment of for depression is increasingly important because pharmacological treatment is effective only in a certain portion of the population. According to Belle and Singh (2008), individuals vary widely in their response to drug for various reasons, but genetic factors are estimated to account for 20% to 95% of variance. The reason for such wide variance is because genetic influences on drug metabolism interact with physiologic and cultural, behavioral, and environmental characteristics of a person to determine the outcome from treatment with any medication.

Treating Mexicans for medical conditions and mental disorders requires an understanding of cultural beliefs and ethnic pharmacology. For example, Mexicans have a higher sensitive to antidepressants than individuals of most cultures (Purnell & Paulanks, 2013).

Barriers to Service Delivery and Treatment

One of the most pervasive barriers to services for people with disabilities in Mexico is the lack of publicly available community care programs and facilities. According to Rodriguez et al. (2015), the lack of public services "in Mexico City or anywhere in the country is inexcusable given the tremendous international attention this issue has received – including condemnation by United nations human rights authorities" (p. iii). According to Gonzalez and Alvarez (2016), the most relevant challenges for the Mexican mental health programs reside in (a) strengthening prevention programs, (b) establishing primary care as the articulating axis for mental health, (c) improving the training of health workers, and (d) improving patient rehabilitation and reinsertion. Other persistent barriers include underreporting of mental health disorders, stigma, and misconceptions associated with beliefs about depression and other mental disorders. Because of these sigma and misconceptions and linking psychotropic medication use to illicit drug use, many Mexicans (and Latinos) may resist treatment with medications and prefer psychotherapeutic treatments ("talking cures," counseling; Kramer Guarnaccia, Resendez, & Lu, 2009). There is a strong belief that people should be able to control their symptoms on their own (*hay que ponerse de su parte* – one has to do one's part or make an effort to get better). Thus, needing to take medication is seen as a sign of weakness or laziness and means that the person is not working hard enough to get well (Kramer et al.). See Discussion Box 20.1 for examples of stigma and popular misconceptions about depression.

Discussion Box 20.1

Stigma and Misconceptions about Mental Health Disorders

Depression is only in the mind and can be cured by positive thoughts.

Mental illness is a sign of personal weakness.

Strong and mature individuals do not suffer from mental illness.

Men cannot have depression.

Nobody can die from depression, so what does not kill you makes you stronger.

Seeking mental health treatment is simply an escape for those who cannot handle their daily problems.

Mental illness is a sign of loss of control.

Questions

1. What are the cultural influences to consider?
2. How does gender impact stigma about MH?
3. How is locus of control interpreted in Mexican culture and how is it applied to the conception of MH?

Adapted from Gonzalez and Alvarez (2016) and Kramer et al. (2009)

In treatment of mental health disorders, research suggests a direct correlation between poor insight and poor treatment adherence and, consequently, with poorer outcomes and functioning (Buckley et al., 2007; Gomez-de-Regil, 2015). In a study to examine barriers to initiation and continuation of mental health treatment among people worldwide with common mental disorders, Andrade, Alonso, Mneimneh, and Wells (2014) found the two major barriers to seeking and staying in treatment are low perceived need and attitudinal barriers. In addition, a desire to handle the problem on one's own was the most common barrier among respondents with a disorder who perceived a need for treatment. Attitudinal barriers were more important than structural barriers to both initiating and continuing treatment, with attitudinal barriers which dominate for mild-to-moderate cases and structural for severe cases. The most commonly reported reasons for discontinuing services were ineffective treatment, followed by negative experiences with treatment providers. In a survey of treatment of mental disorders for adolescents in Mexico City, Borges, Benjet, Medina-Mora, Orozco, and Wang (2008) found less than one in seven respondents with psychiatric disorders used any mental health services during the previous year. Of those who did use services, respondents with substance use disorders reported the highest prevalence of service use and those with anxiety disorders the lowest. Furthermore, about one in every two respondents receiving any services obtained treatment that could be considered minimally adequate.

When looking at Mexican migrant farmworkers, Dolan and Lee (2010) contend there is sufficient evidence that indigenous cultural belief systems and practices combine with the social, political, and economic marginalization of indigenous Mexican communities in Mexico and the USA to limit access and use of mainstream health care. According to Linares (2008), indigenous groups are subjected to racism in Mexico, and they come to the USA with a fear of mainstream institutions because of prejudice, discrimination, and violence experienced in Mexico. In their study of indigenous and Mestizo Mexican migrant farmworkers, Dolan and Lee found indigenous participants reported significantly higher stress compared to groups, and the prevalence of culture-bound syndromes (recurrent, locality-specific patterns of aberrant behavior and troubling experience that may or may not be linked to a particular DSM diagnostic category, Kramer et al., 2009) was highest for indigenous females. The more Spanish-literate indigenous respondents were less likely to report culture-bound syndromes, and more educated indigenous respondents were less likely to have a depressive syndrome. Indigenous participants living in the USA for 7 years or more were significantly less likely to report poorer emotional/mental health and reported significantly lower stress. The conclusion is that adult education and literacy programs may be especially effective emotional/mental health intervention for newly arrived indigenous Mexican-origin migrants (Dolan & Lee).

The family and community, highly valued in Mexican culture, may present as a barrier to treatment as well. Individuals with mental illness or symptomology often fear rejection by family members and members of the community. Therefore, they deny and conceal their illness, with the purpose of protecting the family reputation (Kramer et al., 2009). The family, in turn, reinforces and supports the denial.

Status of People with Disability and Mental Illness

A report by *Disability Rights International* (DRI) asserts "behind the closed doors of Mexico City's institutions for people with disabilities, atrocious abuses are taking place that amount to nothing less than torture" (Rodriguez et al., 2015, p. i). People across all ages with disabilities in these institutions are described as being denied treatment, sexually abused and exploited, left to languish in filthy dehumanizing conditions, are restrained, and exploited in unimaginable ways. The DRI report explicitly asserts social service authorities have acted in concert with private institutions to exploit and cause increased mental and physical disabilities of residents with disabilities to the point that is life threatening. Overall, Mexico's national and city authorities have been aware of these practices for years and have not taken the action necessary to end the abuse of people with disabilities and have failed to implement systematic human rights monitoring for any institution for people with disabilities (Rodriguez et al.). In the following section, two populations are discussed, older adults and inmates.

Older Adults with Disabilities Although Mexico has a lower level of socioeconomic development than the USA, the levels of disability prevalence among older adults are lower in Mexico (Wong, Gerst, & Michaels-Obregon (2010). Wong, Gerst, and Michaels-Obregon suggest with Mexico's higher infant and childhood mortality rates, it is likely that only the "strongest" survived into old age and are relatively more robust than older adults in the USA. The Mexican older population (age 60 and older) is expected to grow to 15% of the total population by 2027 (Wong & Palloni, 2009).

Older Mexican adults with long-term disabilities have a high prevalence of abuse. Giraldo-Rodriguez, Rosas-Carrasco, and Mino-Leon (2015) found a 32.1% prevalence of abuse among older adults with long-term disabilities without cognitive decline. The most frequent type of abuse was psychological at 28.1%. Almost 58% of respondents reported one type of abuse, 34% reported two types, and 8% reported more than three types. Psychological with financial exploitation was the most common combination of two types of abuse. Individuals age 80 and older who experienced psychological, physical, and sexual abuse had three or more disabilities, emotional symptoms, a history of hospitalization, limited education, and negative self-rated health and were unemployed. With the addition of being married or living with a partner and living in an urban area, the same variables were associated with those who experienced financial exploitation (Giraldo-Rodriguez et al.).

Data from the National Institute of Statistics and Geography (INEGI) reported a decrease of 29% in the number of deaths related to mental and behavioral disorders between 1998 and 2008 but an increase of 33% between 2008 and 2014. The decrease was among younger individuals (age 29 and below), and the increase was among older adults (ages 50–54) (Estadisticas de Mortalidad, Consulta Interative de Datos, n.d.). In addition, the increase in mortality associated with mental health disorders occurred for both men and women. Gonzalez and Alvarez (2016) speculate that the global financial crisis of 2008 and the Mexican government's war against drugs (which started in 2006) "may have created an atmosphere of social unrest" that contributed to these trends (p. 3).

Mental Disabilities in the Criminal Justice System In a review of the rights of persons with mental disabilities in the Mexican criminal justice system, Puente and Benavides (2013) assert that "for any criminal justice system to work effectively, it is essential to take into account the rights of persons with mental disabilities given that they are more likely than the rest of the population to be involved in criminal proceedings, either as defendants, victims or witnesses" (p. 6). Mexico reports about 2% of its criminally incarcerated population have a mental disability, yet Mexico has no effective system for identifying people in the criminal justice system with mental disabilities, and by definition it also becomes clear that Mexico does not have an adequate system for diversion or treatment (Puente & Benavides, 2013). Furthermore, Puente and Benavides emphasize the urgency of action to ensure effective access to justice for persons with mental disabilities. Movement toward prison reform in Mexico came closer realization in 2016 when the senate unanimously approved a wide-ranging prison reform bill, the National Penal Enforcement Law. However, it is too early to tell if these measures will be enough to revamp a prison system badly in need of improvement. The National Penal Enforcement Law is designed to ensure that Mexico prisons will no longer perpetuate massive violations of the rights that are guaranteed by the constitution. More specifically, the bill (a) prohibits the use of torture and other cruel, inhuman, or degrading disciplinary measures, (b) bans the use of solitary confinement for more than 15 continuous days, (c) establishes gender-specific rights for incarcerated women, and (d) grants immediate eligibility for release to nonviolent offenders convicted of possessing less than 5 kilograms of cannabis, as well as those convicted of stealing less than the equivalent of about US $340 (LaSusa, 2016). LaSusa stresses that although prison reform is greatly needed, the use of taxpayers' money for prisons, especially those aimed at improving conditions for inmates, is generally unpopular.

Latin-American countries have the highest incarceration rates in the world, and these rates are inversely related to the level of service access and investment. Furthermore, the conditions in these prisons range from poor to extremely harsh, overcrowded, and life threatening (Almanzar, Katz, & Harry, 2015). In Mexico, access to psychiatric services is difficult because of the limited number of psychiatrists. In addition, many of these psychiatrists are inadequately trained and lack forensic expertise. According to Walker et al. (2013), overcrowding in prisons has negative effects on the physical and mental health of individuals living in these conditions and can be detrimental to their general well-being because of increased prevalence in infectious disease and psychiatric disorders.

In a study of connectivity between mental health and contextual of prison environment factors among prisoners in Mexico, Albertie, Bourey, Stephenson, and Bautista-Arredondo (2017) found severe depression, substance abuse, and heavy substance use were prevalent. The protective factors for severe depression were recent visitors, conjugal visits for any substance abuse, and prison employment for heavy substance use. Physical attacks were associated with increased prevalence of depression, time served with both any and heavy substance use and overcrowding with any substance use.

Mental Health Legislation and Policy

In 1990, the Latin-American countries signed the Caracas Declaration, which emphasized the human and civil rights of persons with mental disorders and promoted restructure of the psychiatric care system from hospital-based to community care alternatives (Levav & Gonzalez-Uzcategui, 2001). Over the years, this declaration has been ratified, expanded, and operationalized through documents such as the Brasilia Principles on the Development of Mental Health Care in the Americas in 2005 (Brasilia Ministry of Health of Brizil, Pan American Health Organization, & World Health Organization [WHO], 2005), and the Panama Consensus in 2010 (Pan American Health Organization, World Health Organization, 2010), as well as the Mental Health Intervention Program (mhGAP), a resource published by WHO to assist professionals in the clinical management of priority conditions in nonspecialist health settings (WHO, 2010). Currently, disease-specific policy does not exist in Mexico. According to Gonzalez and Alvarez (2016), however, the government has given more emphasis to mental health with the Specific Action Program for Mental Health (SAPMH) 2013–2018 (see https://www.mindbank.info/item/5884). The SAPMH is aligned with the National Development Plan 2013–2018 and the Health Sector's Plan. The strategy is called Miguel Hidalgo's Model for Mental Health, and emphasis is placed on (a) the promotion and prevention of MH disorders, (b) with the aim of increasing early diagnoses, (c) increasing quality of care, and (d) reducing cost of care. The program is a tool to assist in multidisciplinary coordination on MH, as well as promote the organization of services through a community-based network (WHO, 2017).

In an analysis of the mental health legislation in Mexico using the *WHO Checklist on Mental Health Legislation*, Sotelo-Monroy Cavazos-Olivo, Sauer-Vera, and Rosa-Donlucas (2014) found legislation in Mexico adequately covers 37 (28.9%) of the 128 items examined, 42 (32.8%) items were covered to some extent, and 49 (38.3%) items were not covered at all. Sotelo-Monroy et al. assert their findings are consistent with earlier about the right to the protection of MH and the regulation of MH services in Mexico, in which "Mexican law confers excessive deference to medical decisions on controversial issues in which there might be an involvement of the user rights" (p. 17). In an earlier study, Gorn, Solano, Medina-Mora, Basauri, and Reyes (2013) evaluated the key indicators that characterized the Mexican mental health system using the World Health Organization Assessment Instrument for Mental Health Systems (WHO-AIMS). The author found of the total budget for health, only 2% is allocated for mental health, and, of that share, 80% is used in the operation of psychiatric hospitals. Other results are (a) the pivotal point for MH care is in the psychiatric hospital; (b) there are very few psychiatric units in the general hospitals, few residential establishments, and few services targeted specifically to care for children and adolescents; (c) access is limited because of the centralized healthcare system, with the majority located in large cities; (d) only 30% of primary care services have protocols for the evaluation and treatment of mental disorders; and (e) in the MH facilities, the ratios of psychiatrists, other physicians, nurses, and psychologists per 100,000 population are 1.6, 1.3, 3.4, and 1.5, respectively. Clearly, increased funding, more specialists, periodic in-service training for personnel at the first level of care, and greater participation by the general public are needed.

Overwhelmingly, the literature is consistent in observation that implementation of community MH in Mexico is slow and there remains a significant gap in the healthcare system, which prevents people from accessing mental health services, particularly in rural areas. According to Gonzalez and Alvarez (2016), “evidence indicates that, in addition to the medical relevance of the subject, the individual and societal costs associated with mental disability must be considered when prioritizing polices in the health sector’s agenda” (p. 3).

Recommendation to Improve Services

Mental health care in Mexico is not only in need of improvement, but many would argue it is in need of a complete overhaul. Consideration to the needs of offenders with mental health disorders increases the urgency for improvement. Recommendations for immediate action to ensure effective access to justice for persons with mental disabilities are associated with Mexico’s recent ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRDP). Mexico needs to urgently address the following areas (Puente & Benavides, 2013):

1. Internationally accepted legal standards for determining criminal responsibility
2. Effective assistance of counsel for people with mental disabilities
3. Accessibility in criminal justice proceedings
4. Supported decision-making for people with mental disabilities
5. Jail diversion programs to the community with community-based support
6. Community support to assist with reintegration to society (p. 8)

Puente and Benavides emphasize further that immediate improvements to protect people with disabilities in the criminal justice system (CJ) could be made by (a) creating new accommodations within the CJ system, (b) training CJ officials and criminal defense attorneys, and (c) improving community-based diversion and support programs. Implicit in these recommendations for improvement is promotion of the ethical principles of autonomy, beneficence, fidelity, justice, nonmaleficence, and veracity.

The Sequential Intercept Model (SIM) is another approach Mexico’s CJ system can implement to identify where changes need to happen to have a real impact (Griffin, Heilbrun, Mulvey, DeMatteo, & Schubert, 2015). The SIM provides a basis for thinking about the five intercept points (law enforcement, initial detention/initial court hearing, jails/courts, reentry, and community corrections) and how the CJ system can make changes to impact the number of people with mental illnesses coming to and staying in jail/prison. The SIM can be used to identify points in the system where officials could implement new policies, practices, or programs (Griffin et al.).

Other more general recommendations for improving the rights of persons with disabilities are presented by Rodriguez et al. (2015):

1. Draw up comprehensive plans to integrate all people with disabilities into the community.
2. Bring new placements to an end of children in institutions.

3. Avoid dumping people into the community with no services.
4. Develop an individualized plan of support.
5. Create family-based alternatives for children.
6. Allocate resources for crisis intervention and crisis stabilization (pp. 23–24).

The premise of these recommendations is the right of people with disabilities to have the legal capacity to be protected by Mexican law. The intent is to bring Mexico's mental health law and psychiatric commitment procedures into compliance with CRPD to ensure that people are not arbitrarily detained in institutions (Rodriguez et al.).

Often, change starts as a grassroots initiative. Persons with disabilities and family organizations should become advocates to move the mental health agenda forward. Advocates should organize to influence government on mental health policies and laws and to educate the public on social integration of people with disabilities (Funk, Minoletti, Drew, Taylor, & Sacaceno, 2005). The importance of advocacy and activism has taken hold in Mexico in which ex-patients (i.e., Colectivo Chuhcan, http://colectivochuhcan.webnode.mx) are policing the mental health system and demanding an end to the systemic problems. Because of government's piecemeal and unfulfilled promises to improve the system repeatedly fall short, with money and attention focused on short-term or cosmetic improvements instead of the development of long-term care and rehabilitation (Zabludovsky, 2013), the need for advocacy and activism has become increasingly critical. Advocacy can result in positive outcomes such as reduction in stigma and discrimination and improvements in policies and practices of governments and institutions (WHO, 2009).

In an era of technological advances, e-treatment and e-counseling should be explored as viable alternative to providing treatment to persons with disabilities and mental health disorders. Virtual intervention is proven effective in various settings and across different populations. Moreover, the use of virtual intervention may offer a means to reduce stigma associated with mental illness. That is, e-treatment does not call attention to the person receiving services.

Finally, people with disabilities and mental health disorders need services from multiple providers. Any approach to services should include an interdisciplinary approach, for example, leaving mental health care to the domain of primary care providers. However, research suggests implementation of mental health services in primary care clinics in Mexico will be difficult because the system is already fragile and underfunded, service issues, language and cultural issues, care recipient characteristics, and issues with lack of knowledge (Martinez, Galvan, Saavedra, & Berenzon, 2016). Much more effort is needed to ensure that mental health programs are effectively diffused as community-based and inclusive of comprehensive services including screening, assessment, and treatment components.

Summary

Many people in Mexico living with disabilities and/or mental health disorders encounter barriers when they seek treatment and often experience abuse. A substantial gap exists in mental health care. Cultural beliefs about mental health disorders serve to further stigmatize and prevent individuals from seeking help. Untreated mental health disorders adversely affect other health conditions. Harsh conditions in institutions and prison for persons with disabilities are recognized as dismal by international disability rights organizations. Often, legislation is inadequate or not implemented. Overall, mental health and disability services in Mexico are impaired by poor socioeconomic conditions, lack of infrastructure, and limited knowledge and inexperience of psychiatric service providers.

Resources

2013–2018 Plan Nacional de Desarrollo: http://www.dof.gob.mx/nota_detalle.php?codigo=5343100&fecha=30/04/2014

COAMEX: http://coalicionmexico.org.mx

Global Disability Rights Library (Category Mexico): https://www.widernet.org/portals/index.php?PortalID=18&PortalPageID=4546&view=pub

Improving Health Systems and Services for mental Health: http://apps.who.int/iris/bitstream/10665/44219/1/9789241598774_eng.pdf

Movement for Global Mental Health (MGMH): http://www.globalmentalhealth.org/category/country/mexico

Portal del Empleo: https://www.empleo.gob.mx

Learning Exercises
Self-Check Questions

1. What did Armendariz and Saladin (2012) emphasize as important to understanding the difference in the route to passage of the Americans with Disabilities Act and the Ley General para la Inclusion de las Personas con Discapacidad?
2. What is the importance of family participation in the health care of members in Mexican culture?
3. What are the stigmatizing terms and meanings used to describe mental illness in Mexico?
4. What are the cultural beliefs about the cause of illness in Mexican culture?
5. What is the status of intervention services for people with mental illness in Mexico?

Experiential Activities

1. Examine the ADA and the Ley General para la Inclusion de las Personas con Discapacidad and compare and contrast them. Discuss the strengths of each law and identify areas you consider to be in need of improvement.
2. Participate in a Study Abroad Program in Mexico in rehabilitation counseling, counselor education, counseling psychology, or social work. Consider one of the following activities: (a) schedule to visit in a mental health institution or prison/jail and interview staff about their needs to more effectively provide services to the population with whom they work, (b) become a trainer of mental health service providers, or (c) assist in the development of an advocacy plan.
3. Work with a local group of Mexicans/Mexican Americans/Latinos to educate about mental health disorders and to address culture-bound syndrome.

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21

System of Service Delivery for People with Disabilities in India and Impact in Rural Areas

Amy D. Spriggs, Elizabeth Siereveld,
Molly Baldridge, Kaylee Ortiz, and Thomas Young

Overview

India is one of the oldest civilizations in the world, dating back to 2500 BC (Allchin & Allchin, 1993). Geographically, it is the seventh largest country in the world lying entirely in the Northern Hemisphere. India stands apart from the rest of Asia with its borders marked by mountain ranges in the north and by the sea in the south to give it its own distinct geographical ethnicity. India's total population is 1,210,569,573, making it the second largest country in the world (India Register General and Census Commissioner, 2011). India is a culturally rich and diverse country with many factors contributing to the unique views on family, spirituality, and differences.

Given the size of India and the diversity found within and between geographical regions, this chapter will not cover the totality of disability or rehabilitation in the country. Rather, this chapter will focus on experiences in the state of Karnataka in southwest India, an area the authors of the chapter have spent time. Karnataka is the eighth largest state by area and ninth largest state in population; it is made up of 30 districts, 176 subdistricts (taluks), 347 towns, and 29,340 villages. The census data from 2011 lists the population of Karnataka at 61,095,297. Bangalore, the state capital, is the most populated district which accounts for 15.75 % of the state's total population (India Register General and Census Commissioner, 2011).

Karnataka is one of the prominent states in all of the country in terms of economic development. Karnataka tops India in biotechnology, a leading industry in the state. Bangalore is often referred to as the "Silicon Valley" of India because of its large focus on business and innovation (Byker & Austin, 2014). Although the large cities like Bangalore are considered world leaders in manufacturing, the majority of the workforce is engaged in farming-related activities. This is especially true in the smaller rural villages located around the state (Planning and Statistics Department, 2006).

Mayasandra, a large farming village located in Turuvekere of Tumkur District, Karnataka, includes 925 families. Mayasandra has a total population of 3778 residents based on the 2011 census. The village has a higher literacy rate than the state of Karnataka (i.e., 87.31% in Mayasandra compared to 75.36% in Karnataka). Males have a literacy rate of 92.45 % compared to 82.29 % of females (Census Population, 2015). Mayasandra's

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A.D. Spriggs (✉)
Associate Professor of Special Education, University of Kentucky, Lexington, KY, USA
e-mail: amy.spriggs@uky.edu

E. Siereveld • M. Baldridge • K. Ortiz
University of Kentucky, Lexington, KY, USA

T. Young
Jim & Suzanne Elliott & Family Professor of Pediatrics, Kentucky Clinic L449, University of Kentucky, Lexington, KY, USA

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staple crops are rice and coconuts, which are common for many rural villages in the southern part of India due largely to the climate. Along with rice and coconuts, farmers grow many fruits and vegetables, including potatoes, beans, lettuce, bananas, and oranges. Many of these crops are sold within the village, but some are sold in Northern India, where the climate is more suited for growing coffees and teas. In addition to farming, many women from the village work as tailors or storekeepers; some find work on a local flower farm, which exports their goods to shops in Bangalore.

Traditional Cultural Values and Strengths

India's culture is shaped by social class, family, and spirituality, which have been greatly valued throughout history. All of these work together to inform cultural traditions and rituals observed by many. This is largely defined by beliefs and values dominant in the country and its people. The uniqueness of Indian culture lies in its strong caste (social) system and individual family values. The caste system is a system of ranking people by their jobs and ritual status (Jacobson, 2007; Llewellyn, 2015). Historically, there are four castes that people belong to: priests, warriors, merchants, and servants. Recently, "government census and anthropological surveys have identified hundreds [of castes] in South Asia" (Llewellyn, 2015, p. 78). This caste system is a structure people are born into, marry within, and continue to live within while on earth. Family structure and spirituality are both impacted by this system.

Family In India, family has been the foundation for everything else for many generations (Mullatti, 1995). India is considered a collective society, putting things such as family honor, dependability, and unity before individual needs (Hui & Triandis, 1986). Families are often found living in the same geographic region, with up to three or four generations living in the same home (Chekki, 1996). This is especially true in the more rural areas, where farming is common (Niranjan, Nair, & Roy, 2005). Younger generations are faced with taking care of elders, as well as those with disabilities. In this model, life decisions for things like career choice or marriage partner are made jointly with the family (Mines, 1988).

Males and females raised in Indian families experience these family values in different ways (Ram, Strohschein, & Gaur, 2014). Although several family structures exist (e.g., joint, nuclear), in many places in India, the eldest man still working in the home is typically in charge of the home. Boys and girls are raised the same throughout early adolescence. As young adults, boys will often attend college and marry after graduation; when they move back into their parent's home, they will often assume the role as head of the household, and their father will retire. Girls, on the other hand, are more often married by their late teens or early 20s. They will move into the home of their husband and his family.

Several possible factors may explain this family adhesion, especially in rural areas of India. Many have speculated that social class and religious beliefs play a large part in this (Mines, 1988; Williams, 2013). It is common for parents to arrange marriages for their children within the same social class (Mines, 1988). Many living in India also have a strong belief in karma and dharma that tie into the repeating cycle of life. The principles of karma and dharma include treating others with the highest dignity and respect because what goes around comes around (Tiwari & Pandey, 2013). This translates into the belief that parents who support their children will raise children who will support them when it is needed. Although these two factors certainly exist within many families, Niranjan et al. (2005) found that socioeconomic status, land ownership, and age and education of the head of the household were more indicative of specific family structures. For those living in rural India, joint families are more likely to live with extended family.

Spirituality India is made up of groups belonging to different races and religions where people who practice different religions can coexist while living next to each other. Many villages, such as Mayasandra, have two predominant religions: Hinduism and Islam. The villagers practice their religions separately but live together in harmony. About 80 % of the people living in India, and Mayasandra, practice Hinduism; 13.4 % practice Islam (Anees, 2015).

India is often identified as the birthplace of Hinduism (Lorenzen, 2016). Hinduism has many different variations and is made up of several sects (Doniger et al., 2016). Hinduism is believed to be a pathway to a strong connection to God, as God is everywhere and in everything. Temples decorated by various gods and goddesses can be found all over India. The most common gods include: Brahma, Vishnu, Shiva, and Devi (Jacobson, 2007; Lorenzen, 2016). Hinduism is linked to the caste system. People working in a lower caste believe that religious purity can alter the caste system they are reborn into (Jacobson, 2007; Llewellyn, 2015). This purity is extended into other areas of a Hindu's life. For example, people avoid contact with body fluids, feet, the left hand, and often members of different castes (Llewellyn, 2015). Body fluids such as blood and saliva are thought to be pollutants, feet are considered impure, and the left hand is viewed as unclean. The hand preference is commonly observed because the right hand is used for eating, and the left hand is typically used for bathroom purposes. Purity and pollution influence social groups and their interactions (Henderson, 2002).

Islam, the religion practiced by the Muslim community, is the second most common religion practiced in India (Anees, 2015; Williams, 2013). Hinduism evolved gradually as a way of life, while Islam was founded by the Prophet Muhammad (Doniger et al., 2016; Schimmel, Rahman, & Mahdi, 2016). Muslims believe all people are created by God, and God's will influences both destiny and fate. They believe that there is divine intention and order in the universe; that is, everything is created to function independently, but under the direction of God. They also believe they are called (by God) to help those in need, which leads to a strong sense of community among various families (Schimmel et al., 2016).

Views on Differences Although there is a strong sense of family unity and a deep sense of spirituality for many living in India, these two factors can negatively impact views on differences, especially if those differences include disabilities. For those who believe in karma, a disability is often seen as a punishment for things done in a previous life (Singh, 2000). The punishment is meant to be something a person must go through to get to a better place in their next life, so others often do not intervene. This has led to decades of no services for individuals with disabilities. Many believe that along with karma, disabilities can be passed from one person to another or from one generation to another. Therefore, some people with disabilities in India are hidden because they can cause social and physical burdens on their families and caregivers (Janardhana, Muralidhar, Naidu, & Raghevendra, 2015). For example, many marriages in India are arranged, leading to hiding family members with disabilities because their siblings will not be able to find suitable marriage partners. Before an arranged marriage can take place, both families have to agree that the marriage is suitable. Many believe that if a child in the family has a disability, future generations will also have a disability (Janardhana et al., 2015).

Although the views on differences still exist, there is a growing trend toward acceptance for those with disabilities. There are services available in many large urban cities for those that can afford them. However, most people with disabilities live in rural areas of India making it hard for them to receive the services that they need.

Rate of Disability

According to the 2001 Indian census, 2.13 % (i.e., approximately 21 million people) of the population in India is considered disabled (Chavan & Rozatkar, 2014). The census is based on data that can be subjective, so that number has been estimated to be as high as 6–8 % (i.e., as many as 70–90 million people; Anees, 2014; Janardhana et al., 2015). Seventy-five percent of these individuals live in rural areas, and only 49 % are literate (Anees, 2014). Disabled classifications include sight, hearing, mental, physical, and speech disabilities (Ministry of Statistics and Program Implementation, 2011). The Indian government has realized that the mind-sets of its people need to change, and they need to begin accepting individuals with disabilities. Thus, several government task forces and committees have started providing services and making more places accessible for persons with disabilities. This process is slow, but the change has started and will continue to grow and progress as citizens in India begin to accept differences on a more global level.

The Integrated Education for Disabled Children (IEDC) was passed in 1974. It was one of the first initiatives to improve education through integration and inclusion for individuals with disabilities (Sharma & Deppeler, 2005). In 1986, The National Policy on Education promoted inclusion with a goal to integrate "the handicapped" in all aspects of the community (Singal, 2006). A program that the Government of India funded, the District Primary Education Project (DPEP), was founded in 1994 to integrate individuals with mild to moderate disabilities in schools. In 1996, the Persons with Disabilities Act (PWDA) was passed to mandate this integration (Sharma & Deppeler, 2005). The PWDA was put into effect because of the lack of resources individuals with disabilities had in India. It provided legislation that required nondiscrimination, producing more accessibility to education, employment, buildings, transportation, and communication. The Sarva Shiksha Abhiyan (SSA) is a policy of zero reject that was put into effect in 2001. It mandated that no child could be denied education due to their disabilities. IEDC was revised in 2009 and is now known as Inclusive Education of the Disabled at the Secondary Stage, which allows an individual to enroll in 4 additional years in an inclusive setting after the completion of their 8-year elementary schooling (Ministry of Statistics and Program Implementation, 2011; Sharma & Das, 2015).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which India is a signatory under Article 9, requires governments to ensure accessibility to information, transportation, physical environment, communication technology, and accessibility to services and emergency services. The Indian government has a vision of an inclusive society in which equal opportunities and access are provided for growth and development of persons with disabilities to lead productive, safe, and dignified lives. This initiative by the Ministry of Social Justice and Empowerment conceptualized the "Accessible India Campaign" as a nationwide flagship campaign for achieving universal accessibility that will eventually enable persons with disabilities to gain access to equal opportunities, live independently, and participate fully in all aspects of life within an inclusive society. It has been mandated that by 2019, 50 % of all government buildings in major cities in India are to be accessible to all individuals, regardless of disability, by a collective effort by all government agencies.

The Biwako Millennium Framework was created by the Economic and Social Commission for Asia and the Pacific (ESCAP) in 2002. This was a framework for action, which was produced in an attempt to promote inclusion and rights for individuals with disabilities in the twenty-first century. The framework was made up of a series of targets, which focused on organizations of persons with disabilities and related family and parent associations; women with disabilities; early detection; early intervention and education; training and employment (including self-employment); access to buildings and public transport; access to information and communications, including information and communications; and assistive technologies (Ministry of Statistics and Program Implementation, 2011).

System of Service Delivery

Although the idea of inclusion of students with disabilities has been accepted on many levels, the subject still proves to be a topic of great controversy, especially in developing countries. In recent years though, many Asian countries have begun to embrace the idea of integration and inclusion within their schools. In India specifically, its national government has enacted a number of initiatives in order to promote integration and inclusion of children with disabilities including IEDC, 1974; Project Integrated Education of the Disabled (PIED), 1987; and PWDA, 1996

(Sharma & Das, 2015). The PWDA is much like the legislation in the United States passed in 1975 as it could impact the access to education for millions of children with disabilities. However, when looking at the effect of this system of delivery, one must consider the great demographic divide between India's urban and rural areas, specifically the differing incomes and resources. Throughout India's history, as in most developing countries, the incidence of poverty is higher in rural areas than in urban areas. As India has continued to develop, the gap between rural and urban areas has continued to grow. For example, in the 1960s the ratio of the rural poverty rate to the urban poverty rate in India fell within the range of 1:1–1:2, but in the 1990s the ratio leaped to 1:4 (Datt & Ravallion, 2002). In an epidemiological study of child and adolescent psychiatric disorders in various areas of Bangalore, it was found that there were no significant differences between prevalence of disabilities in rural versus urban areas (Srinath et al., 2005). The prevalence of disabilities tends to be the same in both rural and urban areas. However, due to the division of resources, those living with disabilities in rural areas do not have the same access to the supportive services found in urban areas. Therefore, in order to discuss service delivery, the context in which it is delivered must be considered.

While the delivery of services for those with disabilities in India may look different from that of Western cultures, it is still happening in one form or another. For example, within Bangalore, a major urban area, there are several segregated support schools for those with disabilities. One organization in particular, the Spastics Society of Karnataka (n.d.), was founded with the goal of, "conscious, conscientious and constant endeavor in maximizing the potential of children with special needs Inclusiveness in all aspects of daily life," as well as, "establishing their rights to be part of the community." Some other organizations include Apoorva Center for Autism, Autism Society of India, and Communication DEALL. These programs most often serve a specific population of children, they can be expensive for families, and acceptance into the programs can be difficult. In addition, children with more severe disabilities can often be disregarded when considering admission into programs. For example, Beautiful Gates Special School in Mysore, India, states in their admission policy:

> From time to time there may be applicants who would require extraordinary attention that would reduce the resources available to other students or that may pose a potential risk to other students. Beautiful Gate Special School must consider the best interest of all its students and, therefore, reserves the right to not accept such applicants or dismiss such students (n.d.).

Outside of these larger organizations, service delivery is funneled through smaller programs, funded by nonprofit organizations, without involvement or resources from the government. This is typical for service delivery in rural areas in India (Singal, 2006). For example, Nava Nirmana Charitable Trust (NNCT) in the village of Mayasandra is a small segregated school funded by several organizations, including the Rotary Club of India. Although these segregated schools are positively impacting the rural communities, the lack of funding and available resources does impact the amount of intervention that can be implemented. For example, within the Spastics Society and many other large organizations in urban Bangalore, staff are trained, and students are given access to many resources, including wheelchairs, walkers, therapy and sensory materials, assistive technology, and adapted curriculum. Within the rural areas, teachers have no access to training. Specifically within NNCT, only two walkers are available, there are no wheelchairs (nor would they be accepted), and physical therapy is done with a mat and stander. A curriculum is not available for the students and/or teachers, although they do pay to receive advice from a larger organization (e.g., Spastics Society of Karnataka, Communication DEALL) once a month.

Once individuals with disabilities become adults, options for rehabilitation services are rare. The Spastics Society of Karnataka offers follow-up programs for those with disabilities if they are unable to be mainstreamed at the secondary level, including community-based rehabilitation, where the adults with disabilities are provided the opportunity of working in a "sheltered workshop" where they learn the skills needed to make materials that are income generative. These items can include bags, clothes, wallets, trinkets, etc. Overall, few programs exist for those with disabilities that have exceeded the age limit of special education services. Much of that may be attributed to the many cultural barriers that prohibit those with disabilities the opportunity to become an active member in India's society.

Discussion Box 21.1

Mayasandra is a large farming village that grows crops like rice, coconuts, fruits, and vegetables. There are many jobs that can be created from these farming activities. Some examples include planting and cultivating the crops and selling the crops within the village. Although there are many jobs associated with the actual planting, harvesting, and selling, there are some other jobs that need to be created, so everyone can be productive during nonfarming seasons or droughts. Some jobs that are common to villages like Mayasandra include tailors, shopkeepers, and teachers.

Although the opportunity for various jobs exists in small villages, many times people with disabilities are not given the opportunity to have jobs. They are often left at home while their parents work if they are not in school. Many times those with disabilities are seen as burdens to the family. This can be because they cannot work independently or slow down the work of the rest of the family.

1. What are some jobs that could be completed by individuals with disabilities in regard to farming activities?
2. What are some jobs that could be created to be completed by individuals with disabilities when farming isn't possible?
3. How can the teachers at NNCT facilitate teaching job-related skills for the adolescents while they are still in school?
4. How can teachers and families work together to ensure the job skills taught are important, realistic, and sustainable?

Barriers to Service Delivery

As mentioned above, one barrier to service delivry is the demographic divide between India's urban and rural areas, but there are many more to be considered. Most of the barriers could fall into one of five categories: government, social, attitudinal, family, and access to services. Although India's government has initiatives in place to encourage education of those with disabilities, no laws currently mandate education for this population. India also does not have the funding or teaching power to enforce such laws (Hernandez, 2008). India's government acknowledges that not much of their national budget is devoted to educational expenditures. The country relies heavily on nongovernmental organizations to supplement basic education costs, yet they continue to struggle in providing the funds for universal education in an already limited budget (Hernandez, 2008). On top of lacking funds, India does not have teachers that have been appropriately trained or equipped to work with those who have disabilities (Hernandez, 2008). In addition, India lacks the support needed in classrooms to provide accommodations and individualized support, with the average class ratio being 1 teacher to 40 students (Hernandez, 2008).

Socially, children with disabilities are presented with cultural preferences that keep them from excelling in their communities. For example, in India it is not appropriate to eat with your left hand, not due to right-hand dominance but because of the cultural significance of the right hand being the "clean hand" (Emeneau, 1987). If a student has a physical impairment impeding eating with their right hand, they are often kept out of schools. Society also deems male figures with a medical degree as having a more prominent impact in their culture, putting priority on medical treatments for those with disabilities versus educational needs (Anees, 2014). India is also a culturally diverse society that differs from city to city and village to village. A big part of culture is the language spoken. Within India, there are in excess of 1500 languages, both official and unofficial, spoken across the country (Sengupta & Saha, 2016). Unofficial languages are especially evident in the rural villages. The language spoken in Mayasandra, for example, is Kannada. This is a language recognized and understood within their small area of the state. Within typical schools in Mayasandra, students are being taught both Kannada and English but not within segregated schools. Within NNCT specifically, students are only taught Kannada, limiting their vocabulary and who they can talk to.

Those with disabilities are not only limited by society but can at times be limited by their families as well. Many families will deny access to services because deprivation is everywhere and if they don't believe the services will increase the child's potential contribution within the household; it is not worth their already limited time and resources (Anees, 2015). Additionally, lack of education creates an attitude of a "one-time fix," such as a pill or medical diagnosis that will clear the symptoms of the disability. The authors of this chapter have witnessed this in their work with families with disabilities. Many families are desperate to have a surgery or prescription to "fix" the problem. Due to some families believing that having a family member with a disability is karma, families may be reluctant to enroll their child in school (Limaye, 2016). Many families of females who have disabilities choose to prepare them for being wives and taking care of their future home and family (Anees, 2014). Women marry into other families, so their immediate family is uninterested in investing in their education while growing up. Therefore, approximately 68 % of school-aged females are not enrolled in school (Kohama, 2012). In Karnataka, the literacy rate of women with disabilities is 7 % compared to 46 % overall for females within the state (Limaye, 2016). In addition, many families are not aware of special schools that are available to meet their children's needs through specially trained personnel. When families seek medical help, medical professionals may recommend sending individuals with disabilities to regular schools. While inclusion is important in schooling, regular school teachers in India are untrained in the teaching methods needed for children with disabilities to reach their fullest potential (Limaye, 2016).

It is estimated that there are 900 schools for the hearing impaired, 400 schools for those with visual impairments, 1000 for students with intellectual disability, and 700 for children with physical disabilities (Bagga, 2007). Since there are millions of individuals with disabilities in India, there are not enough schools with special education services. In addition to the lack of available schools, many schools are not equipped to accommodate individuals with disabilities. According to Kohama (2012), only 18 % of SSA schools are "barrier-free." Barrier-free environments are those in which individuals with disabilities can move around safely, independently, and freely. In schools that are not barrier-free, some children may have difficulties in bathrooms, libraries, classrooms, and playgrounds. It is expensive to add modifications to buildings, so in countries already lacking resources, such as India, making buildings accessible to individuals with disabilities is not viewed as a priority (Kohama).

Within the more rural areas, access to service can prohibit a child with disabilities from receiving special education. The majority of the families in these areas use public transportation to get from rural to urban areas, which can be both costly and time-consuming. For example, Mayasandra is located within a geographically isolated area. Traveling by bus from the rural village of Mayasandra to the urban area of Bangalore can take up to 3 h and cost as much as 150 rupees, one way. This much traveling would also mean time away from work, which most families cannot afford. Aside from that, many children are not able to ride public transportation due to physical impairments, behavior, or other needs related to their disability. These families cannot afford to move to urban areas due to the influx of prices and necessities needed to live there. The resources in urban areas are not accessible nor are they necessarily appropriate for those with disabilities in the rural communities. Not only are urban area services hard to access, services in rural areas aren't always accessible. Unlike Western culture, the majority of families do not own or have access to an automobile. This leaves them walking in order to reach local services, which is oftentimes impossible due to physical impairments, rough terrains, and many days of unbearable temperatures. NNCT has recognized these problems and provides families with a ride in the school van. It only travels a certain radius and is only accessible for each family twice a week. In addition, there are not special schools located in every village. Some families must travel hours to get to the closest school, making attendance not feasible. This leads to a strain on accessing available services for much of India's population who have been diagnosed with a disability.

Discussion Box 21.2

In rural Karnataka, the median annual household income is 18,900 rupees. Being as transportation to bigger cities can cost up to 300 rupees round-trip, it is nearly impossible for families to access the services desired for those with disabilities. Assuming that a round-trip would cost 300 rupees for an individual to have special education services 5 days a week for 8 months, it would cost a family 48,000 rupees. In addition, if a family were to travel to the larger cities 5 days a week, they would be missing work.

In some villages, like Mayasandra, specialized schools exist, where teachers and therapists from larger cities visit once a month to provide support. There are some issues with this model that do not equate to the services from the larger specialized centers: teachers in these schools do not have the training, the resources are lacking, the time students are in school is limited to 2 days if they ride the bus or 6 days if a family member can bring them (often resulting in that family member staying at the school for the day).

1. If a family member brings a student to school 6 days a week and stays with them, do you think there are ways that family member could be used at the school to enhance service delivery?
2. What are some alternatives to traveling 5 days a week for 8 months to access the services in the larger cities, assuming those services do not exist in the village?
3. What are some suggestions you could make to teachers and/or family members to help increase the access to services for the children who can only come to school 2 days a week?

Strategies to Enhance Services

Although there are many barriers to service delivery in India, especially in the rural areas, there are systems in place to promote access to appropriate services that can serve as models. In Mayasandra, there is already an established international collaboration with the United States. An overall shift in focus to inclusive education could lead to positive outcomes for all students in India. Community-based rehabilitation (CBR) is a model that might lead to better services for all individuals with disabilities in India, including adults.

International Collaboration Another possible way to overcome the barriers to service delivery would be for countries like India to look to established programs for rehabilitation. For example, the United States has a long history of providing special education and rehabilitation services to those with disabilities. While many of the laws in the United States govern those services, the Acts put into place by the government in India can create the path to better services for more people with disabilities in India.

History There has been growing international collaboration within the rural village of Mayasandra. In 2009, a medical brigade from University of Kentucky Shoulder to Shoulder Global (STSG) had an exploratory trip to two villages in southern India, one was Mayasandra. This was coordinated with a retired surgeon from Bangalore who had returned to the village he grew up in. Initial thoughts were that STSG might assist the community in developing a primary care center similar to the STSG in Ecuador. After a health camp in the village, where around 500 patients were assessed, it was clear to the pediatric team that many children with special health-care needs were not receiving intervention services. The team met with the local community leaders to discuss the special health-care needs of local children. Through strong local leadership and support from STSG, Mayasandra established a nonprofit organization, NNCT, to organize and run a program for children with disabilities. NNCT and STSG organized a community-wide survey to identify the level of special needs in the population. This survey identified 3.5 % of children with special needs, primarily neurodevelopmental. The initial model was to partner with the Spastics Society of Karnataka to train local members of the community for a 6-month-long training. Once trained, they returned to Mayasandra and opened a center, serving children there and in surrounding communities. Children were bused from nearby villages. The Spastics Society sent a team once a month to the center to oversee treatment plans and work with staff they had trained. In 2013, a group of physical therapists accompanied the doctors to assess the physical needs of the children in and around the community. Many families that had children with disabilities traveled to see the doctors and physical therapists; the majority of the children with physical disabilities also had intellectual disability. In 2014, special education faculty from University of Kentucky accompanied the group as an exploratory trip to evaluate the needs of the children attending the clinic. It was determined that the majority of the 100 children seen had developmental and physical disabilities. The 2013 camp in Mayasandra sparked the need for a true interdisciplinary assessment of the students coming to the clinic. Each year the group traveling to Mayasandra has grown to include doctors, therapists, teachers, students, and families.

The services STSG offers to this self-contained school for children and adolescents with disabilities are unique for India in that it is truly interdisciplinary. Teams work collaboratively to assess children in ten domains: environment, academic, cognitive, communication, motor-sensory, social, emotional, adaptive, behavioral, and medical. Most of the time the groups have doctors, therapists, teachers, and students from India and the United States working together with the family. The assessment provides a way to determine what the needs are for the child and the family; suggestions can be made for school, home, and access to the community.

In India, many of the special schools are run by local doctors. The NNCT school in Mayasandra is no different. A local surgeon saw a need and worked with STSG and Spastics Society of Karnataka to create a school for students with various types of disabilities. The surgeon and a group of teachers started a school in a two-room clinic. It has grown to a two-building school with classrooms, a therapy room, a cafeteria, offices, and bathrooms.

The teachers had very little training, and the doctor set the school up in a medical model where many kids came to school and waited to be called in for their turn in school. In 2015, the special educators and physical therapists began including professional development training for the teachers and staff in the school. They modeled easy strategies and provided a list of baseline activities for each child they assessed. The thought was if the teachers knew where to start and how to teach, they would be better suited to meet the needs of the diverse population they served. It became clear that this was not enough. In the Spring of 2016, the University of Kentucky, with the help of Rotary Club of India, sent a teacher to live in Mayasandra for 4 months. During this time, the teacher worked alongside the staff and administration in order to better train and equip them to provide services to students. She also was able to educate staff and families on disabilities and answer questions regarding their children that they had never been able to ask. Although language and cultural differences proved to be two major barriers when working alongside NNCT, she was also able to teach and learn throughout the experience. A lot of what she did involved working one-on-one with staff to model teaching strategies, including systematic instruction. The majority of the staff believed behaviors could not be fixed and many children could not be taught, so she also worked alongside them to show that behaviors can be both learned and unlearned, giving them strategies to change behaviors and increase learning. She worked together with administration, demonstrating different ways to monitor student progress in order to track student learning. This progress monitoring was designed to inform instructional decisions, be shared with family, and demonstrate the school's work when requesting funding from different organizations. Ultimately, the teacher worked with them, giving them a toolbox of sustainable strategies that they could use, making the school more independent and less dependent on large organizations and Western professionals.

Case Study

Naveen is a student who has been attending NNCT for 3 years. He receives both physical therapy and special education. He is currently 8 years old and lives with his mom, dad, brother, and grandma in a neighboring village close to Mayasandra. His family is native to the village, and his dad and grandmother operate a storefront that is connected to their house. His mother cuts hair for a living. Naveen travels by bus twice a week and is dropped off by his mother the other 4 days. When first starting NNCT, Naveen was not able to sit up on his own, move from sitting to standing without assistance, balance without assistance, or use the bathroom independently. These physical limitations made it impossible to attend school with his typical peers. While at school, Naveen receives physical therapy services that help to strengthen muscles needed for gross motor skills (e.g., sitting, walking) by a physical therapist. After lunch, Naveen receives 1–2 h of special education. For 3 years, Naveen received physical therapy daily, and his family was taught how to practice with him at home. The teachers integrated physical therapy into his classes, and he slowly began to build the muscles needed to become more independent. Naveen is now able to sit and stand on his own, as well as walk with assistance. Although he is still unable to use the bathroom or walk independently, he will be enrolling in a general education school starting next school year because of the advances made while attending NNCT.

Questions:

1. What role might the integration of Naveen's physical therapy into his classes have on his progress?
2. What role might training Naveen's family in his physical therapy exercises have on his progress?
3. If Naveen's family had waited until he was 10 to bring him to NNCT to begin receiving physical therapy and special education, do you think he would still be transitioning to the general education school?
4. What could the teachers and therapists at NNCT do to facilitate more inclusive placements for their students in the general education schools?

Future Although the school in Mayasandra has come a long way, there is still much that needs to be done. Training teachers at these smaller specialized schools in realistic and sustainable practices is critical. Considering a shift toward inclusive education would be a next logical step in teacher training. Looking into a model like CBR would be a meaningful way to ensure services for those with disabilities expand into adulthood.

Sustainable Training Practices Teachers working at NNCT need to be trained in the assessment protocol so that children need not wait until the annual STSG trip for an initial assessment. They are currently a part of the assessment process, so teaching them how to identify the critical needs of the children would be invaluable. Teachers need additional instruction in creating and maintaining a schedule, classroom procedures, small and large group teaching, and age appropriate instruction.

This process was started when the teacher from the United States lived with them for 4 months. This program is still, however, run by a doctor. It is critical that the schedule resembles more of a school day and less of a doctor's office. They need to learn evidence-based practices when delivering behavioral and academic instruction to students, so bigger gains can be made. The training for these teachers has been so limited. They rely on monthly visits to know what skills to target and, if there is time, how to begin to teach them. It would be empowering if the teachers were taught a few high-impact instructional strategies that they could use with a variety of skills. For example, they could be taught to use system of least prompts to teach chained tasks and constant time delay to teach discrete tasks. Behaviorally, the teachers need to learn how behavior principles influence behavior change. The data collected for academic tasks and behaviors need to be monitored to ensure it is being collected with fidelity and being used to make instructional decisions. This is a program that was also started when the teacher from the United States was visiting; however, a system needs to be in place to ensure this practice is continued. Although there will continue to be new needs identified, regardless of what is implemented, the STSG team needs to ensure that all recommendations are realistic and sustainable given all of the factors described in this chapter.

Shift to Inclusive Education The Ministry of Human Resource Development is responsible for training regular education teachers, whereas the Rehabilitation Council of India is responsible for training special education teachers (Kohoma, 2012). This makes the shift toward inclusion more difficult due to the separation of training, gap in curriculum, and the lack of collaboration of training between regular and special education teachers. Educators throughout India are not trained to design and implement special education practices (Sharma & Deppeler, 2005). In order to promote inclusion in both regular education and separate schools across India, an inclusive curriculum and inclusion training needs to be included to teaching practices (Limaye, 2016; Parua & Kusum, 2010).

All students in India have been given a right to education with the National Policy on Education passed in 1986 (Singal, 2006). There are differing philosophies about where children with disabilities should be educated. Some argue for special schools, where students can excel in a school that is designed to meet their needs; other argue for integrated education, where at least some children with disabilities should be educated with their typical peers. Inclusive education has been a topic of conversation for almost 20 years. In India, inclusion is not for all children. "A child with disabilities must fulfil a range of prerequisites before being included into the mainstream" (Singal, 2006, p. 360). The prerequisites include things such as ability to interact with peers, quick acquisition of new skills, and ability to attend to tasks.

Current barriers exist, making inclusive education for all nearly impossible. One issue is that assistive devices are often not accepted by society (Singal, 2006). For a student to be included appropriately, it is likely assistive devices will be needed. Another issue is that some schools are structured around a strict curriculum (e.g., National Institute of Open Schooling) (Singal, 2006). For some students with disabilities, an alternative curriculum might be necessary.

Regardless of barriers to inclusive education, the fact that it is the topic of conversation is promising. Students with disabilities are being included when they meet the prerequisites. As more children with disabilities are being educated in general education schools, there is a possibility that teachers will become more confident, and institutes of higher education will begin intentionally training teachers in appropriate methods. These factors are what led the United States to more meaningful inclusion; if India stays on a similar trajectory, true inclusive education could become a reality in the future (Singal, 2006).

Community-Based Rehabilitation CBR is designed to ensure people with disabilities reach their fullest potential (Crishna, 1998). To do this, CBR works to ensure accessibility to all of the things a person would need access to

Research Box 21.1

See Parua and Kusum, 2010.

Objective: The objective of this study was to determine what teachers believe about children's ability to learn and problem behaviors while in inclusive settings. The authors looked at the differences between urban and rural settings and men versus women.

Method: Authors developed a 23-question survey. It was given to 300 teachers, 150 in urban settings and 150 in rural settings, equally split between female and male teachers, in Himachal Pradesh, India. All teachers worked in inclusive schools. For comparison of urban to rural and males to females, mean, standard deviation, and t-Ratio scores were used to determine differences in views on ability to learn and problems for children with disabilities in inclusive settings.

Results: Teachers in both urban and rural settings had similar beliefs about children with disabilities and their ability to learn and problems encountered in inclusive settings. Female teachers were more likely to have positive attitudes toward learning ability for all students within inclusive settings than male teachers.

Conclusions: There was no difference in views between urban and rural settings on the belief that inclusive education could be beneficial for the learning and behavior for children with disabilities. There was a difference between female and male views, with the females having more positive attitudes toward inclusive education outcomes for individuals with disabilities. Overall, the results support the inclusive teaching framework.

Questions:

1. How do the results of this study mirror the cultural issues faced by those living in India?
2. Since this study shows that inclusion is viewed to have a positive impact on the learning and behavior of students with disabilities, what impact could this have on the future of special education and rehabilitation in the future?
3. What are some possible factors that could be attributed to the similar results between urban and rural schools? What are some possible factors that could be attributed to the differences in results between male and female teachers?

(e.g., community, services, social activities). The accessibility should be designed in authentic settings, those used by people without disabilities. To design programs for a person to achieve independence and social acceptance in India, the factors described earlier in the chapter (e.g., family, spirituality) must be taken into consideration. India's culture is well suited for the CBR approach since family unity and community cohesiveness are common (Janardhana et al., 2015).

Summary

Traditions, values, beliefs, and education have been discussed through this chapter and the impact that each have on individuals with disabilities as well as their families. Family and spirituality are two of the main foundations that individuals in India live by. Families stick together throughout generations, and spirituality plays a major role in the acceptance of individuals with disabilities. Throughout this chapter the obstacles of individuals with disabilities in India have been discussed. Lack of transportation, teacher training, and religious views, among many others, have been barriers for individuals with disabilities receiving educational services. The expenses to receive such services, as well as the location of services available, cause barriers to families seeking help, especially in rural India. Emphasis has been placed on the educational advances that are needed in order to increase the number of individuals with disabilities receiving education as well as an improved value of education that they are receiving. Teacher training, inclusive education, and CBR are a vital part in the educational system in other countries. Therefore, these recommended practices could produce a solid foundation toward an educational system to enhance the education of individuals with disabilities in rural India.

Resources

Factors Influencing the Accessibility of Education for Children with Disabilities in India: http://ger.mercy.edu/index.php/ger/article/viewFile/236/217

Government of India: Ministry of Statistics and Programme Implementation: http://mospi.nic.in/.

Inclusive Education in India: A Country in Transition: http://intldept.uoregon.edu/wp-content/uploads/2012/12/INTL-UG-Thesis-Kohama.pdf

Inclusive Education in India: Past, Present, and Future: http://onlinelibrary.wiley.com/doi/10.1111/1467-9604.12079/pdf

Persons with Disability & the India Labour Market: Challenges and Opportunities: http://www.ilo.org/wcmsp5/groups/public/---asia/---ro-bangkok/---sro-new_delhi/documents/publication/wcms_229259.pdf

Learning Exercises

Self-Check Questions

1. What is the division between India's urban and rural areas and the resources that are available or lacking in both?
2. How does the caste system impact views on disability? What impact does this have on the services provided to those with disabilities?
3. How do the beliefs in karma and dharma impact views on disability? What impact does this have on the services provided to those with disabilities?
4. What is the importance of teacher training in the application of special education services? How is this different in urban and rural settings across India?
5. Given the international collaboration between STSG and NNCT, what are some considerations the team from the United States must make when making recommendations for services and program planning?

Experiential Assignments

1. As stated in the text, accessibility of school buildings is an issue in educating individuals with disabilities. Reflect on the buildings you go through daily that support accessibility for individuals with disabilities. Critique the importance of building structures such as ramps, elevators, wide restrooms, etc. Imagine these buildings without such structures and the barriers this would produce for individuals with physical disabilities.
2. Compare and contrast the history of the laws in disability in the United States to those in India. Design a plan for India's government that would be the logical "next step" for disability in regard to education, inclusion, and rehabilitation services.
3. Mayasandra is a large farming village. Outline a list of jobs and skills that could be done as a result of this type of work (e.g., planting crops, selling crops in the village). Create a plan for teaching individuals with disabilities to learn the skills at school and in the community while still in school, as well as a transition plan for employment once they age out of school.

Multiple-Choice Questions

1. Where do the majority of those with disabilities in India live?
   (a) Urban areas
   (b) Suburban areas
   (c) Rural areas
   (d) Both urban and rural areas

2. Where are the majority of the quality services for people with disabilities found?
   (a) Urban areas
   (b) Suburban areas
   (c) Rural areas
   (d) Both urban and rural areas
3. Who organizes and runs most of the special schools in India?
   (a) Teachers
   (b) Doctors
   (c) Nurses
   (d) Therapists
4. Which of the following is/are the main reasons it is hard for individuals with disabilities to receive services in India?
   (a) Limited access to transportation
   (b) Distance to services
   (c) Rough terrains and unbearable temperatures
   (d) All of the above
   (e) None of the above
5. India's culture and subsequently views on disability are shaped by which of the following?
   (a) Social class
   (b) Family
   (c) Spirituality
   (d) All of the above
   (e) None of the above
6. Which of the following has historically had the biggest influence on a person's life in India?
   (a) Government
   (b) Spirituality
   (c) Family
   (d) Social class
7. Who supports teachers in the special education schools in rural villages in India?
   (a) Government
   (b) Families
   (c) Local general education schools
   (d) Special education schools/centers in urban areas
8. Why is communication between regions in India sometimes difficult?
   (a) There are many different languages spoken in India
   (b) People living in one region do not get along with people living in other regions
   (c) Young people only speak English
   (d) All of the above
   (e) None of the above
9. Which of the following would likely be a job for an adult with a disability in Mayasandra?
   (a) Banking
   (b) Farming
   (c) Medicine
   (d) Teaching
10. What is a likely outcome for the international collaboration between NNCT and STSG?
    (a) Medical cure for disability
    (b) Inclusion in general education schools
    (c) Appropriate program planning in multiple domains
    (d) All of the above
    (e) None of the above

Key

1 – C
2 – A
3 – B
4 – D
5 – D
6 – C
7 – D
8 – A
9 – B
10 – C

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Rehabilitation Services in Turkey

22

Deniz Aydemir-Döke and Elif Emir-Öksüz

Overview
This chapter provides general information on disability, rehabilitation, and education services in Turkey, including relevant statistics, legislation, the system of service delivery, and the role of stakeholders, all interpreted through a rural life lens. We recommend possible steps that may help to improve the education, rehabilitation, and employment of people with disabilities in rural areas of Turkey.

The chapter starts with a brief overview of Turkey. This section includes information related to the geographic and demographic layout of the country, internal migration, rural and urban life, the status of ethnic and religious minorities, and cultural values. It is followed by disability facts of Turkey including the prevalence of disability, comparative figures and tables of education and employment of people with and without disabilities, and gender comparisons in education, employment, and disability.

Next, Turkey's first comprehensive disability legislation, Law # 5378, and other disability-related laws and regulations are thoroughly discussed in terms of the impact of service delivery. In addition, we explore a review of the healthcare system, disability benefits and care services, education and rehabilitation, and employment statuses of people with disabilities residing in rural and urban communities within Turkey.

Finally, this chapter presents each title in terms of specific legislations, stakeholders, and urban/rural life. Gender and age are presented as the most important intersecting identities with disability and rural conditions. The chapter ends with a list of recommendations.

Learning Objectives

1. To identify the disability statistics and legislation in Turkey.
2. To explain the available rehabilitation services and the system of service delivery of Turkey.
3. To compare the concepts of urban and rural in Turkey, and its effect on vocational rehabilitation services.
4. To evaluate the problems of rehabilitation service delivery in rural Turkey within social, politic, economic, and cultural frameworks.
5. To recommend possible solutions that take into account Turkey's unique features in order to increase the effectiveness of rural vocational rehabilitation services.

Introduction

Disability is primarily a social condition rather than a biological defect, and social and economic structures affect the quality of life for people with

D. Aydemir-Döke (✉)
Pennsylvania State University, University Park, PA, USA
e-mail: dxa227@psu.edu

E. Emir-Öksüz
University of Cincinnati, Cincinnati, OH, USA

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disabilities (PWD; Erevelles, 2011). Therefore, we would like to provide an overview of Turkey, including some geographic, economic, social, and cultural information, rural and urban layouts, and essential statistics.

A Brief Overview of Republic of Turkey

The Republic of Turkey (Türkiye Cumhuriyeti [TC]) was founded in 1923. Turkey is a democratic, secular, social constitutional state. The capital city is Ankara, and the official language is Turkish (The Constitution of The Republic of Turkey, 1982). Its geographic position is pretty unique, as the country occupies lands in both Asia and Europe. Turkey is a peninsula, surrounded by the Aegean Sea on the west, the Black Sea on the north, and the Mediterranean Sea on the south. It borders Greece, Bulgaria, Georgia, Armenia, Azerbaijan, Iran, Iraq, and Syria (Dewdney, 2016). At the end of 2015, the population of Turkey was reported as 78,741,053 (Turkish Statistical Institute- Türkiye İstatistik Kurumu- [TÜİK], 2016). According to the 2015 data, 49.8% of the population is female, and working-age adults (15–64 years) comprise 67.8% of the total population (TÜİK, 2016).

Due to the extensive employment, education, and health opportunities in the urban and metropolitan areas, many people have migrated from rural to urban areas, especially to the big cities; internal migration has rapidly increased since the 1950s (Dewdney, 2016; Güreşçi, 2012; Yılmaz, 2015). The five largest cities – Istanbul, Ankara, Izmir, Bursa, and Adana – host 40% of the total population (TÜİK, 2016), and these cities get migration from both urban and rural areas of Eastern and Southeastern Anatolia and Black Sea regions (Güreşçi, 2012).

Rural population decreased from 22.7% to 7.9% of the total population between 2012 and 2015 largely because rural communities were renamed and classified as urban communities by 2013 (TÜİK, 2016; Yılmaz, 2015). Although the living and economic conditions and the education and health opportunities have not been reformed, a significant portion of the rural population was included in urban population by 2013 regulation. Definition of rural and urban population of TÜİK is based on the legal recognıtıon of the settlements; yet, “rural” is a fuzzy concept. Development, demography, urbanization, higher education, and industrialization can be indicators of rurality. Compared to other European Union countries, Turkey is extremely high on the rurality index (Gülümser, Levent, & Nijkamp, 2010).

As the constitution of Turkey (1982) defines all citizens as Turkish, ethnic minorities do not have any official status, and Turkey does not keep statistics for ethnic minorities. The main ethnic minorities are Kurdish, Zaza, Arabic, and Laz. More than 90% of the population identify as Muslims, with denominations of Islam including Sunni, Alawi, and Shia. Sunni Islam is adopted by the majority. There are also small populations of Jews and Christians. Christians in Turkey come from several denominations, including Greek Orthodox, Armenian Orthodox, Roman Catholic, and Protestant (Dewdney, 2016).

It is argued that Turkey has a collectivist culture; however, the culture and structure are more complicated than can be explained within a collectivist-individualistic dichotomy (Göregenli, 1995). Generally speaking, interrelatedness and expectations of others are important for Turkish people (Kağıtçıbaşı, 2013). Showing respect, accepting traditional customs, and meeting with social expectations are central values for adults but are less important to the younger population (Aygün & İmamoğlu, 2002). Complying with the social norms is more vital for people who live in smaller areas compared to those in big cities (Kağıtçıbaşı, 2013). Socioeconomic status [SES] may affect values as well, for example, low and middle SES parents prefer raising interrelated and collectivist children, whereas parents from high SES are more interested in raising interrelated and individualistic children (İmamoğlu, 1998). The individualistic culture structure is more prevalent among the people who live in urban areas, those with high levels of education, and are younger (Göregenli, 1995).

Disability Facts and Figures

According to the 2011 national census data (most recent disability statistics), 4,882,841 (6.6% of the total population) people in Turkey have at least one disability (TÜİK, 2011). This prevalence rate is almost half of the rate in 2002, which was 12.29% (TÜİK, 2002). Additionally, the most recent disability prevalence in Turkey appears lower than the average prevalence in world, which is reported to be 15% (World Health Organization, 2011). The World Health Organization (WHO) states that there is an inconsistency in the reporting of disability prevalence between the developed and developing countries, with the latter reporting less due to differences in measurement and data collection (WHO, 2011). This is true in the case of Turkey – both the reduction in the prevalence rate from 2002 to 2011 and the difference between the world average and Turkey are due to the measurement and the cutoff point that was used to determine disability. Turkey used the Washington Group questions in the frame of International Classification of Functioning, Disability, and Health (ICF) 10 in the 2011 data collection; questions covered six functioning areas – seeing, hearing, mobility, cognition, self-care, and communication. Respondents could choose between "no difficulty," "some difficulty," "a lot of difficulty," and "unable to do it at all." Responses of "a lot of difficulty" and "unable to do it at all" were classified as having disability. Thus, the official disability prevalence in Turkey as of 2011 represents only those individuals with severe disabilities.

Learning Exercise 22.1
Explain how does the disability assessment impact overall prevalence of disability.

In Turkey, 57.2% of those with disabilities are women, and 42.8% are men. This discrepancy between women and men increases by age. Among women between the ages of 65 and 69, 27.2% reported having at least one disability. Among men of the same age range, the percentage is 18.3 (see Table 22.1 for proportional differences in functional limitations across genders). This is consistent with the rest of the world – females are reported to have 11–60 % greater disability prevalence across (WHO, 2011). Examining the proportions on the bases of age, 4.9% of the population with disabilities are between the ages of 1 and 6, 16.2% are between 7 and 14, 17.2% are between 15 and 24, 27.7% are between 25 and 44, 18.9% are between 45 and 64, and 15.2% are 65 and older (TÜİK, 2015).

There is also an educational discrepancy between people with and without disabilities in Turkey. Women with and without disabilities are more disadvantaged compared to their male counterparts (TÜİK, 2015). The illiteracy in the general population is 4.5 %; this increases to 23% among PWDs. 10.9% of men with disabilities and 33.4% of women with disabilities are illiterate. Similarly, while 4% of men with disabilities have postsecondary (2 years or 4 years college or higher) degree (compared to 12.1% of the men without disabilities), only 1.5 % of women with disabilities have postsecondary degrees (compared to 8.5 % of the women without disabilities).

Furthermore, the educational attainment of people with disabilities in Turkey varies regarding the type of disability (TÜİK, 2010). While 57.5% of people with intellectual disabilities are illiterate, only 24% of people with emotional and mental disabilities are. If we rank educational attainment by disability type from highest to lowest, people with orthopedic disabilities have the highest proportion of literacy, followed, respectively, by people with mental and emotional disabilities, visual disabilities, hearing disabilities, chronic health conditions, speech and language disabilities, multiple disabilities, and intellectual disabilities (for additional information, see Table 22.2).

There is also a great discrepancy between people with and without disabilities as it pertains to the labor force. According to the 2011 census data, while 47.5 % of the general population is in the work

Table 22.1 Type of disability by sex, 2011

Type of disability	Disabled population[a] (thousand)			Proportion of disabled population (%)[b] (thousand)		
	Total	Male	Female	Total	Male	Female
Persons who have difficulty in seeing	1039	478	561	1.4	1.3	1.5
Persons who have difficulty in hearing	836	406	429	1.1	1.1	1.2
Persons who have difficulty in speaking[c]	507	278	229	0.7	0.8	0.6
Persons who have difficulty in walking or climbing stairs[c]	2313	861	1452	3.3	2.4	4.1
Persons who have difficulty in holding or lifting something[c]	2923	1136	1787	4.1	3.2	5.1
Persons who have difficulty in learning, doing simple calculations, remembering, and concentrating when compared to peers[c]	1412	565	847	2.0	1.6	2.4

TurkStat, World Population Day, 2015
Source: Population and Housing Census, 2011
Figures in table may not add up to totals due to rounding
[a] People who declared that they cannot do at all or have a lot difficulty in the related function were covered
[b] While calculating the proportion of the disabled population, the share at people in total population who declared that they are incapable of doing relevant actions or have much difficulty while doing these activities are taken into account
[c] Population 3 years of age and over were covered

Table 22.2 Population who have at least one type of disability by sex and educational attainment, 2011 (population 6 years of age and over)

Educational attainment	Total population (%)			Population who have at least one type of disability (%)		
	Total	Male	Female	Total	Male	Female
Total	100.0	100.0	100.0	100.0	100.0	100.0
Illiterate	4.5	1.4	7.6	23.3	10.9	32.4
No school completed	19.3	17.7	20.8	19.0	17.6	20.1
Primary school	24.7	21.5	27.8	36.1	38.5	34.3
Primary education/junior high school or equivalent	23.5	26.6	20.4	12.5	19.3	7.6
High school or equivalent	17.7	20.6	14.8	6.5	9.7	4.2
Higher education	10.3	12.1	8.5	2.6	4.0	1.5
Unknown	0.0	0.1	0.0	0.0	0.1	0.0

TurkStat, World Population Day, 2015
Source: Population and Housing Census, 2011
Figures in table may not add up to totals due to rounding

force, this is 21 % among the working-age PWD (TÜİK, 2011). While 35 % of men with disabilities are in the workforce, only 12 % of women with disabilities are employed (TÜİK, 2015).

Based on the statistical evidence, it is evident that PWD are disadvantaged when compared to people without disabilities. Further, women are overrepresented among persons with disabilities, and they face greater disadvantages when it comes to education and employment. Educational attainment varies by the type of disability as well; people with orthopedic disabilities are most likely to have high school and postsecondary degrees, while the lowest proportion is observed among people with intellectual disabilities. These figures provide a perspective about equal access to education and special education services. Those with orthopedic disabilities might be more likely to need physical accessibility, as opposed to special education support, accessible materials, or alternative media.

Learning Exercise 22.2
Discuss the observed educational attainment difference by the disability type. What are the possible reasons of that hierarchy?

Legislation

The European Union adaptation process has increased the emphasis Turkey places on human rights (Meral & Turnbull, 2014). Parallel to this trend, Turkey enacted and implemented several disability laws and regulations, including its first comprehensive disability legislation (Law # 5378) in 2005. This law provides a definition of disability and indicates that an international criterion is utilized for diagnosis, documentation, and classification. It states that inclusion is the basis of any services, and PWDs cannot be forced to live in segregated settings. It also mandates that public places and transportation should be made accessible and that services should be provided in a facility near the person. In addition, it forbids any kind of direct and indirect disability-based discrimination in education and employment (Law # 5378, 2005). For the first time, universities in Turkey are mandated to have a unit to support students with disabilities.

The United Nations [UN] Convention on the Rights of Persons with Disabilities is the most important international declaration that guides Turkey on the treatment of PWD. Turkey signed the UN Convention on the Rights of Persons with Disabilities in 2007 and was ratified in 2009. This agreement is critical for PWD as it requires the national laws and regulations to be more human rights based. Besides, item 10 of the constitution was revised, making equitable services to people with disabilities a constitutional right (Ministry of Family and Social Policy, 2013). Other laws regarding PWD address issues such as tax discounts, disability benefits, responsibilities of municipal authorities, special education, and employment, and they will be presented under related headings.

Stakeholders of Service Delivery

The public institutes and agencies involved in the service delivery system for PWD in Turkey are the (a) Ministry of Health, (b) Ministry of National Education, (c) Ministry of Labor and Social Security, (d) Ministry of Family and Social Policies General Directorate of Services for Persons with Disabilities and Elderly People, (e) Prime Ministry General Directorate for Social Services Child Protection, (f) Social Aids General Directorate, and (g) Turkish Employment Agency General Directorate. In addition, nongovernmental organizations (NGOs), municipalities, and private special education centers are frequently involved toward the implementation of various services for PWDs.

Regarding NGOs, there are 1429 disability organizations throughout Turkey, although they are not evenly distributed across the country. For instance, Istanbul has the highest frequency with 158 disability NGOs, Ankara has the second with 138disability NGOs, and Izmir has the third with 108 disability NGOs. Kars has the lowest frequency with only one disability NGO, creating difficulties for individuals needing disability-specific services from a NGO. Moreover, nationwide, the percentage of PWD having a membership to a disability-related NGO is as low as 5 % (TÜİK, 2010). Bezmez and Yardımcı (2010) argued that because of the sociopolitical nature of the country, disability NGOs in Turkey often are pursuing a charity-based approach to disability instead of a rights-based approach.

This common approach within the disability rights organizations can be observed in the personal approach to disability. Having a charity-based approach, PWD in Turkey may prefer to be passive and just go to the NGOs whenever they need something, instead of being active members or advocates (for more detailed discussion on the functioning of disability NGOs in Turkey, see Bezmez and Yardımcı (2010)). Since local and national NGOs are not very effective, services are mainly provided by public institutes and agencies or for-profit organizations.

Health-Care System

In Turkey, to meet the eligibility criteria for most services provided for PWDs, one must have medical documentation indicating a disability. The medical report of the disability indicates a percentage of disability, which is needed for eligibility of some services. In the disability percentage calculation, there are guidelines specific to each impairment, and both medical conditions and functional limitations are considered. On the disability document, an expert opinion must also be stated for eligibility of services such as special education (Şahin, Altun, & Bilge, 2014), and the documentation can be asked for employment cases (see Discussion 22.22.1).

Discussion Box 22.1

In June 2016, the Ministry of National Education announced that 250 teacher positions are available for people with disabilities. Applicants should provide their diploma, teaching certificate, medical disability documentation, and EKPSS (central employment exam specific to PWD) score at the time of application. People will be employed depending on their EKPSS scores. Ministry of National Education underlined that employed applicants would submit an additional medical committee report from an authorized hospital before they start at their positions. This report should state that the applicant is able to perform as a teacher. All applications should be made in person to the provincial directorates of Ministry of National Education.

People without disabilities are also employed as teacher depending on their central exam scores, but they are never asked to provide a medical committee report about whether they are able to perform as teachers or not.

Please discuss the following questions:

- What does this application mean for people with disabilities?
- Ministry of National Education is responsible to guarantee that students are getting appropriate and sufficient education. For the sake of education quality, the ministry has to take some precautions. Do you agree or disagree with this statement?
- What are the possible outcomes of this application?
- What are the specific challenges related to this procedure for people with disabilities living in rural areas?
- How effectively can a medical committee at a hospital evaluate whether a person with a disability is able to perform as a teacher or not during a walk-in visit?
- How can existing prejudices of medical employee intervene with this process?
- What are your suggestions to resolve this issue?

Because of the strong influence of the medical system in documenting disability for any type of service eligibility, it is important to understand how health insurance works in Turkey. Public health insurance is a constitutional right. With the new reforms in the health-care system, access to health care has been improved (Organization for Economic Co-operation and Development-OECD, 2014) [OECD]. That is, any documented employee and his or her family automatically have health insurance. General health insurance is available to those unemployed; if one has no income or very limited income, his or her general health insurance is covered by the government (OECD, 2014). The government also covers the general health insurance of those with disability benefits.

There are three significant areas of health services for PWDs: diagnoses and treatment, medical rehabilitation, and access to medical devices and technologies such as hearing aids (Toplumsal Haklar ve Araştırmalar Derneği [TOHAD], 2015). However, there are shortages in the availability of specialized hospitals (physical therapy and rehabilitation and mental health care) throughout the east and southeast of Turkey; in the rest of Turkey, the quality of the services is questionable due to hospitals working over their capacity. Overall, accessibility to health-care facilities is often difficult and prevents individuals from getting the help they need. For instance, hospitals and primary care units have been reported to lack accessible restrooms or elevators (TOHAD, 2015). In addition, accessibility of health information for people with visual and hearing impairments is also challenging (TOHAD, 2015). For example, most of the hospitals do not have any sign language interpreters. In addition to accessibility issues, in a study with 1423 people with disabilities, 46% of the people reported experiences of discrimination in health care regarding the physical environment, health-care coverage, service quality, the inability to meet required health service because of disability, and the attitude of the health personnel (Gürboğa et al., 2010). Twenty percent of the participants reported having no health insurance and experienced greater discrimination as a result (Gürboğa et al., 2010).

Overall, access to health care is a constitutional right in Turkey, and vast improvements have been made over recent years. For PWDs, both access to information and access to hospitals need significant improvement in Turkey (Gürboğa et al., 2010; TOHAD, 2015). There are also problems in the availability of specialized health care in Turkey. PWD living in rural areas face additional challenges to health-care access. Special health-care facilities do not exist in certain regions of Turkey, and the capacity of the available facilities is limited (TOHAD, 2015). Furthermore, there is a need for an active effort to register unemployed PWDs to the General Health Insurance, as they might lack the information or resources to apply for it (TOHAD, 2015). In addition, health-care coverage, service quality, specialized care, and the attitude of the health personnel are all areas that require improvement (Gürboğa et al., 2010; TOHAD, 2015).

Disability Benefits and Care Services

In Turkey, according to Law #2022, PWDs can receive monthly disability payments. In order to receive that payment, one needs a medical report indicating that he or she has minimum of 70% disability and is not able to work or take care of him-/herself and his or her family income per person is less than one third of the minimum wage (around 435 US dollars). The maximum disability payment is equal to minimum wage. In 2015, approximately 618,876 PWD received disability compensation (Ministry of Family and Social policies General Directorate of Services for Persons with Disabilities and Elderly People, 2016). In addition, the primary care giver of a PWD might be paid by the government if the PWD is not able to take care of him-/herself, and the family is living in extreme financial hardship.

Turkey has different care options for people with disabilities who do not have self-care or daily living skills. One can go to a residential rehabilitation care center or daily rehabilitation care center, or a care specialist can come to the home of the disabled person to help (Ministry of Family and Social Policies, 2013). In Turkey, there are 98 public rehabilitation and care and family consultation centers and 159 private rehabilitation centers (Ministry of Family and Social policies General Directorate of Services for Persons with Disabilities and Elderly People, 2016). However, the services provided in those centers are not always appropriate for all PWD. For example, they have the word "rehabilitation" in the name yet serve as only nursing homes.

Case Study 22.1

Case of Ali

Ali is a 27-year-old man, who gradually became blind starting during his middle school years; he stopped attending school after middle school. He has been on disability benefits since he turned 18. Ali is living in a small village with his family on the northwest of Turkey. His family makes their living through agriculture and stock breeding. The closest city is in 1 h away, and the closest high school is 30 min away by driving distance. Public transportation is provided once a day by private entrepreneurs.

Ali spends most of his time at home by watching TV and listening to radio. He was never provided orientation, mobility training, and other independent living skills. He is hesitant to go out by himself since the village environment does not have designated pathways or sidewalks. His past unpleasant experiences with the stray animals also discourage him from going out alone. Ali is the only person with a visual disability in the village, and he hasn't met any other person with a visual disability so far.

During his last yearly home visit, Ali's social security benefit counselor suggested that he enroll in a 6-month residential adult rehabilitation program in Istanbul. He decided to take advantage of this opportunity and started by the following semester at the rehabilitation center. He was enrolled in mobility training, daily living, handcrafting, and Braille and computer courses. Although he was happy because he was making new friends and excited about all these new things, he started feeling isolated and withdrawn and felt overwhelmed and a lack of motivation.

A program counselor noticed Ali's mood and approached him to talk. Ali appreciated this invitation and opened himself up to the counselor.

Ali was feeling inferior among his peers. He has been to cities for some family and doctor visits, but he hasn't encountered metropole life. He had never used an elevator or escalator, taken a ferry for public transportation, or seen automatic top or trade mile. He was made fun of upon his questions or actions by his new friends and felt stupid. He thinks that he won't be able to use his mobility training when he returns. He believes that the training does not apply to rural areas. He also complains about the attitudes of administrators. Once he spoke about his concerns related to computer courses, his teacher responded with, "You people come from villages, don't know anything. You always complain. Why don't you try appreciating this opportunity provided by your state to you?" He does not have much motivation for attending classes and socializing with other students.

If you were the program counselor:

1. How would you conceptualize Ali's problem?
2. What are the specific issues related to Ali coming from a small village?
3. How would you work with Ali at individual level?
4. How would you intervene with this case at the program level?

Gürboğa et al. (2010) state that even the PWDs living in urban communities and who are involved with NGOs may be unaware of legislation protecting them against discrimination; this might be valid for rights as well. We can expect that this rate to be higher for people living in rural Turkey. We currently have data on the number of people on the disability benefits; however, this data represents the overall picture; we do not have information about specifics of PWD living in rural Turkey.

Experiential Assignment 22.1
In groups students will compare and contrast the similarities and differences in service delivery to PWD in their country and Turkey; they will make a list of their observations and propose improvement strategies for both countries.

Education and Vocational Rehabilitation of People with Disabilities

Once a family with a child with a disability obtains a medical diagnosis, they are referred to the Guidance and Research Centers [GRCs] for educational assessment (Diken et al., 2012). The Guidance and Research Centers are state-affiliated facilities administered by the Ministry of National Education, and they determine the special education needs of the referred students in each city, province, or town (Diken et al., 2012). TOHAD, which is an NGO that advocates for disability rights, gathered data from GRCs to examine the accessibility conditions and staff profile of GRCs. According to their study, 78% of participating centers do not have elevator, and almost 50% of the centers do not have accessible restrooms. Other accessibility arrangements such as induction loops or talking signals are almost nonexistent in the centers. According to the TOHAD report (2015), a lack of experts (e.g., special education specialists, psychologists, and sign language interpreters) working at the GRCs is a barrier for reliable and valid evaluations as well.

In Turkey, a person with a disability can access education in different settings. Mainstream schools generally offer inclusive education and special education classes (part-time inclusion), but special education schools are sometimes needed depending on the type of disability, availability, and familial preferences. The aim of the inclusive education is to provide education to students with disabilities in the least restrictive environment with special educational support and necessary accommodations. In those settings, the standard curriculum is followed. Special education classes are the classes in the mainstream schools where students with a similar disability are provided some courses together. Depending on the nature of the student's disability, those classes may follow the standard curriculum or might be modified for students with developmental disabilities. Students in special education classes can take some of the classes (e.g., art and music) with their peers who do not have disabilities. Special education schools provide specialized education to students with particular disabilities. Those schools are segregated and are sometimes residential (Ministry of National Education, 2006).

Preschool is mandatory for children between 37 and 66 months old (Ministry of National Education, 2016). During preschool, inclusive education is encouraged by the Ministry of National Education. In some cities, special education schools at the preschool level might also be available (Ministry of National Education, 2016). Across Turkey there are 23 special education preschools, 8 of which are located in Istanbul, 2 in Ankara, and 3 in Sakarya. The other 10 schools are located in 10 different cities; only 13 cities out of 81 in Turkey have one or more special education preschools.

There are residential or daily attending special education schools (elementary and middle school level) for students with blindness or low vision (17 schools), hearing impairments (42 schools), orthopedic impairments (2 schools), and mild intellectual and developmental disabilities (39 schools in elementary, 43 in middle school level). Those schools run from first to eighth grade (Ciyer, 2010; Ministry of National Education, 2016). In addition, students with moderate and severe intellectual and developmental disabilities can obtain education from what are called "Education Application Schools," (266 schools) where the program aimed teaching students basic daily living skills, self-care, and academic training to improve their adaptation to the social and daily life (Ciyer, 2010; Ministry of National Education 2016).

After graduating from middle school, there are special education vocational high schools for students with orthopedic and hearing disabilities. After eighth grade, students with visual impairments continue to mainstream high schools, and there are currently no schools for students with intellectual and developmental disabilities after 8th grade (Ciyer, 2010). Nonetheless, after eighth grade, students with mild intellectual and developmental disabilities can continue their education at vocational training centers (134 centers). These centers provide students with basic vocational skills and offer cultural courses to sharpen their daily living and social adaptation skills. Students with more severe developmental and intellectual disabilities can continue their education in vocational practice centers (221 centers), where the main goal is to teach basic living skills and self-care (Ministry of National Education, 2016).

Students with adjustment problems, learning disabilities, speech impairments, and chronic health conditions are educated in the mainstream schools. Although they are sparse, there are hospital schools for students hospitalized for a long time with due to chronic health conditions (Ciyer, 2010; Ministry of National Education, 2016). Additionally, through the collaboration of governmental bodies, free transportation is available to students attending special education public schools (Ministry of Family and Social Policy, 2013). This is an important regulation to increase the schooling of children with disabilities, especially in rural areas.

Inclusive education is very important for improving the schooling of children with disabilities. In inclusive settings with proper educational support, we can help to integrate students with disabilities into mainstream society and combat the societal barriers of discrimination and segregation. The Disability Law of Turkey states PWDs should not be segregated. Ciyer (2010) recognizes that, in practice, inclusive education is only an option for students with mild disabilities. There are significant problems yet to be addressed in inclusive education, such as the negative attitudes of classroom teachers, the lack of or very low expectations of families, the lack of resources and funding, physical accessibility, overcrowded classrooms, an insufficient number of special education teachers, inadequate teacher training, a lack of instructional adaptations, and invalid or unreliable assessments (Ciyer, 2010; Dikan et al., 2012; Sakız et al., 2015; Sart, Ala, Yazlık, & Yılmaz, 2004; TOHAD, 2015).

Research Box 22.1

Title of the research: The route to "inclusive counseling": counselors' perceptions of disability inclusion in Turkey.

Objective: Examining perceptions and experiences of counselors in relation to inclusive education of students with disabilities.

Method: This study was conducted with six female and six male, a total of 12, school and guidance counselors working in public schools and in Guidance and Research Centers. Counseling experience of the participants ranged from a year to 13 years. Data was collected through face-to-face semi-structured interviews. Transcripts were analyzed through thematic analysis.

Results: The thematic analysis of the interview revealed three main themes: (a) counselor attitudes and practices, (b) paradigms within counseling services, and (c) perceived barriers.

Overall, counselors held positive attitudes toward students with disabilities and the attempts to include them through counseling services. One of the participants said "I cannot accept different schools for different students. Yes, we have many problems which prevent us from including them in the best way, but it is a good start to see them here, at least." Participants also emphasized the unpreparedness of the schools and teachers to work with students with disabilities, which may affect the quality of education that they are offered within the inclusive education. Results showed that understandings of disability were largely based on the deficiency model and difficulties, in their work counselors are diagnosis oriented, and focus on deficiencies. This is forced by the system as well. Counselors perceived that there were inherent problems in the translation of conceptual and methodological knowledge into practices. Lack of collaboration among the school's staff, counselors and families, and role confusion of counselors and work overload were also listed as barriers. In order to express lack of collaboration, one participant recorded that "Administrators are mostly interested in the exam scores of the best students and neglect what we do for students with low ability levels."

Conclusion: Results of this study might inspire policy makers and inform training literature that can help counseling practices be more supportive of inclusion of students with disabilities in mainstream schools.

Questions

1. Why it is important for counselors in mainstream schools to be able to work with students with disabilities?
2. What may help counselors to work more effectively with students with disabilities?
3. Since mainstream schools are not fully prepared for inclusive education, what would you suggest for students with disabilities? Should segregated special education be maintained or inclusive education be forced? Why or why not? Do you have a different recommendation? Sakız et al. (2015).

In addition to public schools and rehabilitation and education centers, there are private special education centers in Turkey where students with medical reports and evaluations from the GRCs can have additional education and rehabilitation support (Cavkaytar, 2006; Diken et al., 2012). The government pays 6 h of individual and 4 h of group sessions per month for the support provided by those centers. A student can get different types of support at those centers, such as learning Braille, behavioral adjustment classes, speech therapy, and physical therapy. While these programs have the potential to support students with disabilities beyond what their schools offer, the number of the hours paid for by the government, unethical practices in those centers, and the quality of education are often criticized (Yavuz, 2015).

Regarding postsecondary education, the number of students taking the national university entrance exam is tremendously lower than for those with no disabilities. Even fewer of them enroll into programs. In 2014, for example, 1,950,163 students with no disabilities and 5378 students with disabilities took the exam. Thus, just 0.27% of the total students who took the national university entrance exam have a disability (TOHAD, 2015). This is probably in part due to the fact that there are barriers in the administration of the exam. For instance, the only option for students with visual impairments is to have a reader and scribe, and there is no guarantee that the reader can read fluently or knows how to read the math symbols (TOHAD, 2015). Moreover, students with visual impairments are exempted from any question having any type of visual such as geometry. This is an indication of the how well those students were taught math and science in K through 12 grades. Students with disabilities face discrimination in enrollment to programs such as music and fine arts; in 2004 a blind student was rejected to register to the music academy, for example, based on her blindness (see Damamme (2016)). Furthermore, those enrolled in to the postsecondary institutes face barriers of not having reasonable accommodations and environmental inaccessibility, all of which increase vulnerability of those students to stress (Koca-Atabey, Dirik, Karanci, & Aydemir, 2011).

Formal education is the most prevalent way to obtain a job for PWD. Overall, Turkey has different options for students with disabilities, ranging from education in a special education school to inclusive education. But the placement of those students depends on their level and type of impairment, the options available to them where there are living, their report from GRCs, and the awareness and advocacy level of their parents. Although inclusive education is an option, it is not working optimally under current circumstances. Sometimes school principals or classroom teachers are not willing to enroll a student with a disability in inclusive education. Special education schools are being forced on the families. There is no data on the quality of the education at the special education schools, classes, and inclusive education classes. It is unclear if the education in those settings is comparable to mainstream settings. For people with disabilities living in rural Turkey, in order to have better access to education, the inclusive education system needs to be improved. Since only a limited number of cities have special education schools, those schools lack the capacity to serve all people with disabilities. Most importantly, having education in nonsegregated settings is a basic right for all individuals.

Learning Exercise 22.3
Explain how schooling of the PWD in rural parts of Turkey can be improved to the best extent.

Employment of People with Disabilities

The Republic of Turkey has laws and regulations in place to support the employment of PWD. The work legislation (Law # 4857, 2003) implements a quota both for government and private sector employers. According to this law, 3% of workers should have a disability if an employer has 50 or more workers. This quota rises to 4% for governmental facilities. Furthermore, this law regulates that social security contributions of PWD employed in private sectors are paid by state funds (Law 4857, 2003). Law #5378 suggests that protected employment places can be established and are financially supported from state funds. Protected employment places aim providing vocational rehabilitation and employment for the most disadvantaged PWD in labor market such as those who have severe mental and intellectual disabilities (Law 5378, 2005). Establishments of which at least 75% of the overall employees are people with severe disabilities can be designated as protected workplaces, and all other details about the formation and progress of these facilities are regulated according to bylaws (Korumalı İşyerleri Hakkında Yönetmelik- Sheltered Work Place Regulation, 2013).

Turkey has been regulating employment of PWD at governmental positions through a separate bylaw since 2014. This bylaw regulates administering a discrete central exam (EKPSS) to employ PWD at designated governmental positions specifically for PWD. People with disabilities who are high school or college graduates are employed depending on their scores, and those who have less education are hired through a drawing (Bylaw #5780, 2014).

The Ministry of Labor and Social Security takes active steps through Turkish Employment Agency (TEA) (Türkiye İş Kurumu - İŞKUR) to increase employment rates among people with disabilities. The Turkish Employment Agency lists three different opportunities specifically for people with disabilities on its website. First, they offer a grant for people with disabilities who want to start their own businesses. Applicants must submit their project to TEA. If approved, applicants must take courses on entrepreneurship before they can receive grant funds. The second option is a grant to the NGOs, universities, government organizations, and municipalities, which have a project that will increase the employment rates of PWD. These projects include starting a business that will employ PWD and organizing vocational trainings to facilitate employment ("İŞKUR Engelli İstihdamı," 2016). The third opportunity is vocational training that TEA delivers in different areas, such as hair designing, bookkeeping assistance, computer treatment, web design, cashiering, and crafting. These trainings are short term and usually do not last longer than 6 months. Trainees are provided basic health insurance and a small daily stipend for transportation and food. All three options are financed through a fund consisting of money gathered in fines from private and government employers who failed to meet the PWD employment quota requirements ("İŞKUR Özürlü ve Hükümlülere Kurs Desteği," 2012).

Some employers prefer paying the penalty instead of having to hire PWD and provide reasonable accommodations. Even many governmental organizations are not able to meet the quota requirement (TOHAD, 2015). Protected workplace applications have both advantages and disadvantages. It can increase the employment opportunities for people with severe disabilities in a protective and noncompetitive environment but may also increase the sense of isolation and make it harder to adapt to a competitive work environment. There is no data that examines the prevalence and efficacy of these protected workplaces. Furthermore, laws and regulations need to be expanded to address all related issues (Çavuş & Tekin, 2015).

The separate central exam (EKPSS) for PWD has its own drawbacks. First, this compensation approach leads to segregation of PWD. The frequency of EKPSS is not specified, and this leads to an inconsistency for employing PWD. Additionally, TOHAD report (2015) reveals that the designated positions are generally unskilled labor and clerical positions. Although this application has significantly increased the employment rates among PWD, the promotion of PWD is considerably limited (TOHAD, 2015). There is no research on job satisfaction of PWD who have been employed by the government. During their time in Turkey, both authors several times witnessed that blind lawyers were employed at clerical positions, wheelchair users hired as cleaning attendants, and many other PWDs working at the positions either under their qualifications or incompatible with their disabilities.

Learning Exercise 22.4

Discuss the pros and cons of having a separate central employment exam for PWD.

Many of these laws and regulations are relatively new. Therefore, the information about how these new regulations impact vocational rehabilitation and employment for PWD is pretty limited. There is no information about how people with disabilities living in rural areas having benefited from these opportunities. Since many of those government agencies and employment facilities are located in city centers, PWD living in rural areas generally need to relocate or commute. At this point, the accessibility and affordability of transportation gains importance. Additionally, some cultural factors might intervene. Relocating for employment in an urban area might be less acceptable for women with disabilities by the family or the society. Definitely, more research is needed to carry the knowledge beyond just the statistics.

Role of Transportation

Transportation is an important factor for accessing education, rehabilitation services, health services, and employment for PWD. This makes public transportation extremely important. There are four main means of transportation in Turkey, including rail, air, sea, and road. In some areas of the country, such as Istanbul, Izmir, and Bursa, all four modes of transportation might be available. Rural areas, on the other hand, predominantly depend on land transportation.

Affordability, availability, and accessibility of transportation can be an issue depending on the socioeconomic status (SES) of a person, his or her place of residence, or his or her disability. Although there are discounts offered to PWD for transportation both between and within cities, for low SES families, for example, paying for the transportation each week for a medical appointment can be an issue. Besides, some rural places may not have public transportation altogether or the transportation from the village to the city center can be limited.

Accessibility might be the biggest problem with transportation in Turkey. Across 41 (of 81) cities, 65% of the main streets and almost 90 % of the roads do not have ramps, 90% of the traffic lights do not have any audible signals, and 49% of City municipalities do not have any vehicles with a lift or ramp (TOHAD, 2015). TOHAD gathered data from 51 city municipalities on the accessibility of public transportation busses. They found that 59% of the total busses do not have any ramps or lifts, 74 % do not have any announcement system for blind people, and 70% do not have an information screen for deaf people. Altogether, public transportation for PWD even in city centers is not mostly accessible. As this data collected in 2014, we hope that at least in city centers, the number of accessible public transportation busses has been improving. For PWD, especially those living in rural areas, having an accessible physical environment and a means of transportation is necessary to access education, health care, employment, and other public services. As such, the accessibility laws should be implemented sooner rather than later.

Learning Exercise 22.5
What is the importance of accessible transportation for PWD in general and for those living in rural in particular?

Role of Intersecting Identities

Many PWDs do not solely or primarily identify themselves as having a disability. People with disabilities are involved in daily life with their multiple intersecting identities and various roles (Artman & Daniels, 2010; Palombi, 2010; Smart & Smart, 2006; Smith, Foley, & Chaney, 2008). When disability intersects with age, gender, race, ethnicity, socioeconomic status, sexual orientation, or religion, people with multiple marginalized identities might be more disadvantaged (Erevelles, 2011; Palombi, 2010; Smith et al., 2008). Additionally, the type of impairment may affect the experiences (Olkin, 1999). For example, Shaw, Chan, and McMahon (2012) found that women with behavioral disorders, who are older than 35 years and come from ethnic or racial minority backgrounds, are the most disadvantaged group in terms of being subject to employment harassment. On the other hand, Caucasian men with physical disabilities who are younger than 35 years are the least disadvantaged group.

Nario-Redmond (2010) found that women without disabilities are categorized as feminine, attractive, and nurturing, and men without disabilities are described as breadwinners, strong, and aggressive. It can be said that this is parallel to existing gender role stereotypes in the society. On the other hand, the researchers found that women with disabilities were not considered as feminine and were hardly associated with nurturing. Instead, women with disabilities were perceived as vulnerable and restricted in parenting options. Men with disabilities were frequently associated with anger. In addition, gender discrepancy among women and men with disabilities were almost nonexistent, while gender-specific differences between people with and without disabilities were significant (Nario-Redmond, 2010). Societal and self-perceptions of PWDs have been identified as incompetent, dependent, asexual, unattractive, weak, and passive (Brodwin & Frederick, 2010; Nario-Redmond, 2010). These research findings support the arguments of Emir-Öksüz (2014) on how gender intersects with disability in Turkey.

Society perceives people with disabilities as unable to fulfill stereotypical gender role expectations such as nurturing or breadwinning (Emir-Öksüz, 2014), and people tend to see people with disabilities separate from their gender (Olkin, 1999). However, this perception does not necessarily mean that women and men with disabilities are treated equally, especially in patriarchal Middle Eastern societies where men are more privileged than women. For example, if a family has both a boy and a girl with disabilities, the family may choose to invest their limited financial resources into the boy and only send him to school (Abu-Habib, 1997). People who live in rural areas in Turkey are mostly economically disadvantaged. Therefore, women with disabilities in rural areas or any disadvantaged part of the country are less likely than men with disabilities to access education or find employment.

Age discrimination is largely overlooked in Turkey. Like gender and disability, society has stereotypes about the elderly population. Elderly people are expected to be dependent and weak and stay home. Elderly people who engage in culturally youthful activities such as working or getting married are often criticized (Çayır, 2012). Stereotypical expectations of PWD and seniors are similar. People with disabilities might be perceived as more ordinary in their older ages, compared to their youth, as long as they fit the expectations for the elderly population. When PWD want to be more active in their older ages, they may face additional discrimination.

Experiential Assignment 22.2
In groups of four, students will discuss the impact of culture on the disability experience. They can focus on the dynamic interaction between concepts such as individualism/collectivism, living in a rural or an urban setting, and other intersecting identities.

Future Implications

Due to the European Union adjustments, Turkey passed legislations (Disability Laws) that grant rights to people with disabilities and ratified the UN Convention on the Rights of Persons with Disabilities. As a result of the legislations, PWD in Turkey have been granted de jure rights to accessibility. However, in application, few improvements have come to fruition (Diken et al., 2012; Meral & Turnbull, 2014; Sart et al., 2004; TOHAD, 2015). For example, the 2005 people with disabilities law ensures the accessibility of public places and gave 7 years to state and private facilities to make the necessary arrangements. After many years, most public places and transportation are still not accessible (TOHAD, 2015). Although by law every citizen has the same rights, in reality the availability and accessibility of services varies greatly depending on rural/urban residency (Bayhan & Sipal, 2011). For example, access to health care is still limited in rural Turkey (Dolekoglu & Gun, 2011). Self-reported adult health and disability significantly differ depending on the geographical region and urban/rural status in Turkey. Education and welfare can protect against the detrimental effects of rural residency and geographic region (Ergin & Kunst, 2015). It is reasonable to anticipate that access to health care is even more limited for people with disabilities in rural parts of Turkey as people with disabilities overall are more disadvantaged regarding the education and welfare. Access to health care is essential to improve the living conditions for people with disabilities and prevention of further disabilities. There is a need for interventions to actively reach people with disabilities who do not have any health insurance.

Beyond this, there is a need for a revolutionary change of perspective on disabilities in the light of UN Convention on the Rights of Persons with Disabilities. The disability service provision is charity-based top-down approach (Bezmez, 2013; Bezmez & Yardımcı, 2010). Moreover disability is over medicalized; as we previously emphasized, having a medical report is essential for eligibility for services (e.g., accommodations in an exam or disability benefits), but the level of disability or the eligibility decisions made by the health committees can differ from one hospital to another for the same person (TOHAD, 2015). At this point, we believe that shifting the focus from the medical aspects of disability to the psychosocial aspects of disability would be more effective. For example, it should be made illegal for employers to ask for medical reports to prove that a person is able to do a job. Due to the lack of information, and biased attitudes of medical personnel on the capacities people with disabilities, such applications impose impenetrable barriers to the lives of PWD.

The Disability Law of 2005 and the regulations on special education mandate not to segregate people with disabilities from the rest of society. Although there are significant problems in the practice of inclusive education (Ciyer, 2010; Sart et al., 2004), it is crucial for improving the educational attainment of people with disabilities in Turkey, particularly in rural regions where special education schools are not widely available. Steps such as improving the number and the quality of special education teachers; supporting classroom teachers, including introductory special education classes in the teacher education curricula; providing more resources for inclusive and integrated education; and improving the accessibility of physical environment would be cultivating the mainstream education for people with disabilities. Moreover, the government should actively implement interventions to increase the schooling of girls with disabilities, as this group is more disadvantaged when it comes to education due to their intersecting identities. Since GRCs are crucial for the education of people with disabilities, the service provided by them should be improved. Most of our suggestions for inclusive education apply to GRCs as well. Furthermore, using interdisciplinary comprehensive test modules that are valid and reliable is essential (Diken et al., 2012). As the national language of Turkey is Turkish, and it is illegal to conduct assessment in other languages, ethnic minorities who are native speakers of other languages are disadvantaged, and this should be changed (Meral, 2015; Meral & Turnbull, 2014). Allowing the use of ethnic minorities' languages would result in more accurate assessments of children and hence more educational opportunities.

Rehabilitation and vocational rehabilitation services require significant improvements in Turkey. First, scholarly efforts that focus on rehabilitation and vocational rehabilitation should be given priority. Most of the available studies focus on special education or medical and physical rehabilitation. Rehabilitation interventions implemented across Turkey, especially rural areas in Turkey, have not been researched enough. The lack of scholarly effort might be due to the fact that rehabilitation is almost nonexistent in Turkey beyond medical rehabilitation and special education. For instance, there are no graduate or undergraduate programs on rehabilitation counseling or psychology or programs that specialize in assisting daily living activities such as occupational therapy and orientation and mobility. Offering programs in collaboration with international institutes to train rehabilitation specialists, and promoting the research focusing on rehabilitation from a psychosocial interdisciplinary perspective, would improve the services provided in Turkey.

Regarding vocational rehabilitation and employment, there is a need for policies and actions to improve gainful and competitive employment of PWD. There are efforts to increase the employment rates of PWD through interventions like quota and special exams. Having a separate national exam for the employment of PWD could help to improve employment rates. However, we believe that the need for a separate exam indicates that the quality of education and accommodations provided for the regular national exams are poor. There is only a need for some special arrangement on the content of the regular national exam for some disability groups, such as people with intellectual disabilities, but there is no need for different content for other disability groups unless the same education content and quality are made available in educational institutes (in primary, secondary, and post-secondary levels). There is a need to assess the job satisfaction and experiences of PWD working in both the governmental and private sectors. There is also a need for career development interventions focusing on the interests, skills, and potential of the person instead of the disability.

Accessing services and information should not be an obstacle any more. Transportation services should be accessible to any PWD. Braille and talking signs, sign language interpreters, ramps and elevators, and any other precautions should be taken in order to increase the accessibility of health, education, employment, and other services. Government websites should immediately and become accessible for all types of PWD.

Turkey should determine future policies with the contributions of disability NGOs and PWD themselves. Policies should address the specific needs of various disadvantaged groups, such as rural citizen's, women, non-Turkish speakers, and elderly PWD. Since accessing information is also limited in rural areas, outreach programs that use traditional information channels such as mail, radio, and television, instead of internet, should be considered. Transportation hassles should be compensated for PWD living in rural areas.

Experiential Assignment 22.3

Students will work in groups and propose a campaign to access to rural populations to create disability awareness and inform PWD and their families about their rights. Students should consider (a) accessibility of their campaign and (b) how to reach the people with disabilities. Students can target a specific disability population.

Summary

Turkey is a developing country with great diversity in regard to ethnicity and religion. According to the last census data, 6.6 % of the population has a disability. PWD are less educated and face higher unemployment than the rest of the population, and women with disabilities are more disadvantaged than men with disabilities. There are national laws (e.g., Disability Law) and international regulations (e.g., UN Convention on the Rights of Persons with Disabilities) guiding Turkey in service delivery, yet there are problems in the implementation of those laws and regulations. Access to health care is of the utmost importance for PWD because in order to receive disability services, a person must have medical documentation proving he or she has a disability. Having social security is a constitutional right, and Turkey has indeed improved the health-care services over the last several years. However, in rural Turkey, access to health-care services can be problematic. PWD living in rural areas have additional barriers to overcome in order to access to health-care facilities, compared to their counterparts living in urban areas or in big cities. There are different educational options for PWD, from special education to inclusive education. Improving inclusive education opportunities across the country would lead to easier access to schooling for those living in rural Turkey. There are a number of suggestions proposed to have better educational opportunities. There are both state and private care options and rehabilitation centers across Turkey. But there is not much information about the services provided in those facilities. There are a number of actions taken by the government to improve the employment of PWD such as having a separate national exam, grants, and occupation courses. Public transportation services are available in city centers but not always in rural Turkey. It is difficult to physically access public transportation across the country, despite the fact that transportation is essential to access other services, such as education and employment, particularly in rural Turkey. Although disability rights and services have rapidly improved within the last two decades, Turkey is still has a long way to go to achieve equal access and opportunities.

Resources

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The research on measurement of disability discrimination.
http://academos.ro/sites/default/files/biblio-docs/837/report_full.pdf
Disability discrimination because of denial of "reasonable accommodations": a very positive connection between the ECHR and the UNCRPD in Çam v. Turkey.
https://strasbourgobservers.com/2016/04/01/disability-discrimination-because-of-denial-of-reasonable-accommodations-a-very-positive-connection-between-the-echr-and-the-uncrpd-in-cam-v-turkey/

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Multiple-Choice Questions

1. Which of the following is not true about Turkey?
   (a) The Turkish population is predominantly Muslim.
   (b) There are more women with disabilities than men with disabilities.
   (c) Independence, autonomy, and freedom are the predominant values of the Turkish culture.
   (d) Turkey occupies lands on both Asia and Europe.
2. Which of the following is true for PWD in Turkey?
   (a) Women with disabilities are more disadvantaged in terms of education compared to their male counterparts.
   (b) People with orthopedic disabilities is the most disadvantaged group for accessing the education.
   (c) 35% of the women with disabilities are employed.
   (d) Employment is not a problem for PWD in Turkey due to mandatory quota.
3. What is the cut of percentage of medical committee report for PWD in Turkey to be counted as disabled?
   (a) 10
   (b) 25
   (c) 40
   (d) 90
4. Which one is not a typical problem for people with disabilities receiving disability benefits and living in rural areas of Turkey?
   (a) Transportation
   (b) Affordable health care
   (c) Accessing disability-related information
   (d) Accessing education
5. A parent who has a school-age child with a disability in Turkey should start by doing which of the following?
   (a) Reaching out to the closest elementary school.
   (b) Taking the kid to the Guidance and Research Center.
   (c) Reaching out to the provincial directorates of Ministry of Education.
   (d) Obtaining required medical committee report confirming disability and stating the percentage from an authorized hospital.
6. Which of the following does not exists within the education system for PWD?
   (a) Separate special schools from first to eighth grade for students with disabilities
   (b) High schools for students with intellectual and developmental disabilities after 8th grade
   (c) Vocational high schools for students with hearing and orthopedic impairments
   (d) Primary level hospital schools for students with chronic health conditions
7. Which of the following does the Turkish Employment Agency not provide?
   (a) Vocational counseling and case management
   (b) Grant for entrepreneurship to PWD
   (c) Grant for the projects of to the NGOs, universities, government organizations, and municipalities
   (d) Short-term vocational training for PWD
8. Which of the following is a problem regarding EKPSS (separate central employment exam for PWD)?
   (a) PWD living in rural areas have to travel for the exam to the city centers.
   (b) This exam promotes segregation of PWD.
   (c) The frequency of the exam does not determined by the law.
   (d) All of the above.
9. Which of the following services/benefits should be promoted so that PWD in rural

Turkey can access to that service right where they are living?
   (a) Disability benefits
   (b) EKPSS (separate central employment exam for PWD)
   (c) Tax discounts
   (d) Inclusive education in mainstream schools
10. What would be the most effective step for Turkey to improve vocational rehabilitation and employment of PWD?
   (a) Passing more laws and increased regulations
   (b) Increasing the penalty for the employees who do not hire required number of PWD
   (c) Applying the existing laws and regulation more tightly, and assessing the outcomes of the current application to develop new policies
   (d) Providing more support to protected workplaces

Key

1. The answer is C, because individualistic culture structure is more prevalent among the people who live in urban areas, have high level of education, and are younger, but this is not the majority of the population. Furthermore, although younger people adopt collectivistic cultural values less than adults, this does not mean that they are totally individualistic.
2. The answer is A. In Turkey, 10.9 % of the men with disabilities and 33.4 % of the women with disabilities are illiterate.
3. The answer is C.
4. The answer is B, because the government provides health insurance to people receiving disability benefits.
5. The answer is D. Proof of disability will be required for the any further step.
6. The answer is B. There is no high school for that group.
7. The answer is A. The Turkish Employment Agency is not providing vocational counseling and case management.
8. The answer is D.
9. The answer is D. PWD can benefit from all other applications regardless of their living location; however, if inclusive education were provided, a student would not need transportation, separation from family, or family relocating. Almost every neighborhood has a mainstream school; however, special education schools are not that much widespread.
10. The answer is C. Turkey has great laws and regulations about employment of PWD. Although there is always room for improvement, the first step is applying the current laws and regulations and assessing the effectiveness of the applications.

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Rehabilitation Services in Colombia

23

Fabricio E. Balcazar, Marisol Moreno Angarita,
Daniel Balcazar, and Eliana Isabel Bedoya Durán

Overview
The chapter describes the incidence of disability in Colombia, the laws that have been introduced to protect the rights of individuals with disabilities, and in particular the concept of community-based rehabilitation (CBR) that plays a central role in the delivery of rehabilitation services in the country. We will analyze the key components of CBR and the ways in which they are being implemented. We will also briefly address some of the rehabilitation issues resulting from the long-standing war conflict within multiple armed groups in the country; this includes a brief review of key legislation that has been enacted to compensate victims of war (at both sides of the conflict) and the specialized rehabilitation services that have been developed to treat the war victims and support their reinsertion into civil society.

Learning Objectives
Upon completion of this chapter, the readers should be able to:

1. Learn about the demographic characteristics of individuals with disabilities in Colombia
2. Understand the construct of community-based rehabilitation and how it is being introduced in Colombia
3. Learn about the role of self-help and empowerment of people with disabilities (PWDs) in the process of implementing rehabilitation services
4. Understand disability related to the armed conflict in Colombia
5. Learn about the efforts by the Colombian government to provide rehabilitation services to the individuals who acquired disabilities as a result of the conflict

Introduction

According to the Pan American Health Organization (PAHO, 2012), the prevalence of disability in Colombia increases with age, from 6.6% for the population from 18 to 29 years old to 45.51% for those who are over 60 years old. The number of people who acquired their disability as a result of the armed conflict in Colombia is

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F.E. Balcazar (✉)
Department of Disability & Human Development
(M/C 626), University of Illinois, Chicago, IL, USA
e-mail: fabricio@uic.edu

M.M. Angarita
Departamento de Comunicación Humana, Facultad
de Medicina, Universidad Nacional de Colombia,
Bogotá, Colombia

D. Balcazar
Rollins School of Public Health, Emory University,
Atlanta, GA 30329, USA

E.I.B. Durán
Programa de Doctorado en Psicologia e
Investigatigacon/Escuela de Psicologia, Pontifica
Universidad Catolica de Valparaiso,
Vina del Mar, Chile

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153,947 (Ministerio de Salud y Protección Social [MINSALUD], 2016, June). With regards to access to the general system of social security and health in Colombia, only 71.5% of the individuals with disabilities are receiving services and almost 79% live in conditions of poverty (MINSALUD, 2014a). With regards to unemployment, the tendency is getting worse for women with disabilities (from 68% in 2005 to 82% in 2012) compared to men (60% in 2005 to 72% in 2012) (MINSALUD, 2014b). Most people with disabilities report that their highest level of education is primary school (43.2% for men and 44.6% for women) or no education (28.8 for men and women), while only 17.6% of men and 17.1% of women report graduating from high school (MINSALUD, 2014a). Prevalence of disability was higher in the Pacific, Orinoquía, and Amazon regions (these are remote areas, scarcely populated by African descendants in the Pacific and native populations in the other regions and with limited services and access). Among all disabled persons, the 2005 census revealed that 44% had a visual impairment and 29% had a physical impartment (Departamento Administrativo Nacional de Estadística [DANE], 2005).

Relevant Legislation The Colombian Congress developed the National System of Disability (NSD) in 2007, which established a series of guidelines, norms, activities, resources, programs, and institutions that allow for the formulation and implementation of disability public policy in the country. The NSD operates in coordination with various institutions at the national, regional, and local levels, with the participation of key actors in the framework of human rights (National System of Disability Law 1145 of 2007) (Congreso de la Republica de Colombia, 2007, Julio 10). In accordance with the legislation, action planning at the national and regional levels is implemented by groups that include consumers with disabilities, service providers, and government officials. These groups are responsible for the implementation of the policies and resource allocation to make sure that the needs of the population of individuals with disabilities are met.

In 2009, the Colombian Congress ratified the United Nations Convention on the Rights of People with Disabilities (UNCRPWD, 2006, December 6), which commits the Colombian government to assure and promote the full exercise of human rights and fundamental freedoms of PWDs without discrimination based on their disability. The Colombian government adopted the definition of disability from the UNCRPWD (2006, December 6), which proposes that disability is an evolving concept that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. In order to comply with regulations specified in the UNCRPWD (2006, December 6), the Colombian government established a national registry system for locating and characterizing PWDs across the country. This is an information system allowing for continuous and up-to-date data collection by state, municipalities, and cities across the country (see MINSALUD, 2016, June). This information is then utilized for the development of plans, projects, and programs oriented at guaranteeing the rights of PWDs in Colombia. In 2013, the Congress of the Republic issued Law 1618 (Congreso de la República de Colombia, 2013) which has statutory status to promote the implementation of the UNCRPWD (Correa-Montoya & Castro-Martínez, 2016).

A key objective of the legislative process is to promote *social inclusion and integral rehabilitation* for PWDs in Colombia. Social inclusion refers to appropriate access to goods and services, participation in the political process, guaranteeing of the citizen's rights, and the elimination of practices that could lead to marginalization and segregation of any type. Furthermore, the process of inclusion promotes access to all social, cultural, political, and economic spaces with equal opportunities for people with disabilities and their families. *Integral rehabilitation* implies a continued provision of supports and services directed at the individual with a disability and his/her family as needed. Services are provided in coordination with multiple agencies. The primary function of these agencies is to facilitate the promotion, prevention, rehabilitation, and social inclusion of PWDs through enhanced access to health and education, as well as increased participation in labor, culture, recreation and sports, communication, and transportation (Republica de Colombia, 2013). Unfortunately, as the data mentioned indicates, there is a gap between the intents of the legislation and the actual implementation and availability of services to individuals with disabilities, particularly in rural areas.

It should also be pointed out that before this system was in place, services to PWDs were based on class status. Families with increased resources were able to afford some assistance. For the most part, low-income PWDs were limited to emergency room services in a few hospitals for the poor and a few NGOs that provided limited access to assistive devices (i.e., wheelchairs). In general, low-income individuals had very limited ways to subsist (begging in the streets), limited to nonexistent access to education or social services, and very limited participation in society. There were also efforts to fund services for people with disabilities through programs similar to the Jerry Lewis Telethon fundraising events. These efforts are based on pity toward people with disabilities and charity as a way to fund services and access to some assistive devices. These initiatives have been rejected by some policymakers and most organizations of people with disabilities because they reinforce negative attitudes and perceptions about disability. In the next section, we examine in more detail the CBR model that is guiding the implementation of rehabilitation policy in the country.

Community-Based Rehabilitation in Colombia

A key construct driving the national policy on rehabilitation in Colombia is community-based rehabilitation (CBR), which has been defined as "a strategy of community development for the rehabilitation, the promotion of equal opportunities and the social integration of all people with disabilities" (Organización Mundial de la Salud, Organización Internacional del Trabajo, & UNESCO, 2004, p. 2). This is a strategy of economic development and social inclusion that addresses the basic needs of PWDs, while creating opportunities and developing the capacities of PWDs to participate and take leadership roles. The process includes the development of PWDs' organizations and support groups, involving the participation of multiple sectors of society and local governments (MINSALUD, 2014c).

The CBR shares the same spirit of primary health care, which represents not only an operational modification of traditional services but expresses a shift in its fundamental values and principles. The CBR model was established to improve access to rehabilitation services for PWDs in low- and middle-income communities through the optimal use of local resources (Organización Mundial de la Salud, Organización Internacional del Trabajo, UNESCO, IDDC, 2012a, b). In the last 30 years, through multiple collaborations with other agencies of the United Nations, nongovernmental organizations, and organizations of PWDs, the CBR model evolved into a multi-sectoral strategy to address the broad needs of people with disabilities, ensuring their effective participation and inclusion in society (WHO, 2015). The CBR model tries to "democratize rehabilitation" by expanding services to people with disabilities in coordination with the local network of primary health-care attention, including access to assistive technology.

The initial attempts at implementing CBR in Colombia started in the late 1980s and were based on different conceptual approaches, operated according to local institutional criteria, and some of them were unaware of the WHO guidelines for implementation (MINSALUD, 2014c). For these reasons, in 2009, staff from the Ministry of Health and Social Protection in collaboration with representatives from disability organizations, foundations, and nongovernmental organizations (NGOs) developed the National Guidelines for community-based rehabilitation following the CBR framework proposed by the WHO (1978, September). This initiative was welcomed by several disability organizations at the national and local levels, which participated in national meetings of CBR, contributed to the development of the guidelines, and participated in internal discussions and in the creation of the Network of Networks of CBR in Colombia. The following is an overview of the objectives set forth by the CBR model:

- To generate coordinated actions for community development between representatives from the civil society and government institutions that promote equal opportunities, poverty reduction, and the social inclusion of persons with disabilities, their families and caregivers
- To foster the social inclusion processes through the development of opportunities, capacity building, and the promotion of participation of organizations of people with disabilities in policy, community, family, and personal contexts, within the framework of collaboration with government agencies and local NGOs
- To integrate initiatives in the areas of health, education, social, livelihood, and social mobility in order to promote the social inclusion of people with disabilities and the effective exercise of their rights
- To facilitate contexts of community and social development that benefit all people and acknowledge their differences (MINSALUD, 2014c)

Guiding Principles of CBR The principles which guide the planning process and strategy development of CBR were derived from the United Nations' Convention on the Rights of Persons with Disabilities (Article 3) which include (a) respect for human dignity and individual autonomy, including the freedom to make one's own choices and to seek independence; (b) nondiscrimination; (c) full and effective participation and inclusion in society; (d) respect for the differences and acceptance of people with disabilities as part of the diversity of humanity; (e) equality of opportunities; (f) accessibility; and (g) equality between men and women (UNCRPWD, 2006).

A key emphasis of the implementation of the CBR strategy was to ensure access to rehabilitation services in remote areas of the country that had limited services and with an approach that sought to complement the institutional system of care. However, with the evolution from a medical model to a social model of disability based on a human rights approach to services and supports, the goals of the rehabilitation process were redefined to a process focused more on helping people claim their right to live with dignity and to achieve social inclusion. The process was implemented at the national level by regional committees, but some local groups had significant insights as part of their deliberation and participation. For example, the group from the local health authority in the capital Bogotá (Buitrago, García, López, & Rojas, n.d.), after analyzing and systematizing the process of implementation of the CBR, concluded that:

- The CBR experiences follow a cycle that is related to the formulation, implementation, monitoring, and evaluation of the programs and in some cases has to return to a process of redrafting.
- Some initiatives emerge over collective actions and eventually generate individual actions from PWDs and/or their families.
- Others initiatives arise from working with children, youth and their families, which are eventually redirected toward processes in collective scenarios.
- Some experiences are developed under a participatory action research framework, and its milestones have two main characteristics—they are temporary and represent the transformation of the experiences of models of intervention in the CBR process and they are in some cases proposed by university professionals.

In this context, the group from Bogotá indicated the presence of other related processes such as:

- The gradual transformation of the concept of disability, which went from being supported on the biomedical model to the social model of disability.
- The enactment of the Convention on the Rights of Persons with Disabilities was a

milestone for the development of the CBR, becoming a human rights approach.

- The formulation and implementation of policies that acknowledge the different approaches and/or populations within the national territory.
- The organizations and social movements of people with disabilities have gained strength in political advocacy and are impacting their local governments (MINSALUD, 2014c).

In short, the regional committees have played a critical role in defining programs and policies that guide the implementation of the CBR at the local and regional levels. The participation of people with disabilities, NGOs, and universities in addition to local government officials from the various agencies involved has allowed the introduction of best practices and a critical review of programs that in some cases have been changed based on their poor results. This is quite unique, since even in the United States, it is often hard to modify federal or state policy even when the empirical evidence suggests that the program(s) may not be generating the results expected.

The Community-Based Rehabilitation Matrix

The CBR Matrix is the framework that identifies the key areas and primary functions of interventions of the community-based rehabilitation approach (see Table 23.1). The table summarizes the five main life areas—health, education, livelihood, social, and empowerment—and identifies the primary functions and main goal for each area as well as specifies the role of CBR in each area. Within each life area, there are five primary functions. The first four areas relate to key personal needs, reflecting the multi-sectored approach of CBR (WHO, 2010a). The final component is related to empowerment as the process of strengthening people with disabilities' capacity to advocate and transform their own communities. This last component is essential to ensure access to each of the other components and thus improve the quality of life and enjoyment of human rights for people with disabilities.

Health Colombia has made remarkable progress in providing health-care services to the population. In 2010, only 4.3% of the population remained without health coverage (PAHO, 2012). In general, the health system is responsible for providing medical attention and rehabilitation services, including assistive devices. Basic health-care services are provided at the local level; however, the health-care system can play a key role in referring people to specialized services outside of their own communities, including PT, OT, speech therapy, prosthesis, and in some cases corrective surgery, particularly in rural areas. Local health centers and regional hospitals provide comprehensive and integrated care, including health promotion, disease prevention, diagnosis, treatment, and rehabilitation of people at all levels of complexity to ensure a higher level of welfare for system users. To this end, it is recognized that the CBR model has a component of community intervention but involves a process of impact on the local political arena, where participation becomes the linchpin. Thus, the processes of health counseling and intervention are geared toward promoting the social inclusion of PWDs. The country is making efforts to improve services in remote rural areas and address structural deficiencies in order to enhance coverage. In fact, recent studies have reported that many people are not satisfied with the institutional health services, because they have many access barriers, and in many locations they exclude disabled people from rehabilitation services (Molina-Achury, Mogollon-Perez, Balanta-Cobo, Moreno Angarita, Hernandez-Jaramillo & Rojas-Castillo, 2016).

Education Between 1980 and 2010, social progress helped to diminish the educational gap between Colombia and developed countries. However, as mentioned in the introduction, the public education system in Colombia is still struggling to accommodate and address the need of all children with disabilities. Access to preschool remains at 48% for all children under 3 and 75% for children under 4 years old; access to primary and secondary education still remains at under 50% (MINSALUD, 2014d). There are

Table 23.1 Community-based rehabilitation matrix

Components	Primary Function	Goal	Role of CBR
Health	Promotion; prevention; medical care; rehabilitation; assistive devices	People with disabilities achieve their highest attainable standard of health	To work closely with the health sector to ensure that the needs of people with disabilities and their family members are addressed in the areas of health promotion, prevention, medical care, rehabilitation, and assistive devices. CBR also needs to work with individuals and their families to facilitate their access to health services and to work with other sectors to ensure that all aspects of health are addressed
Education	Early childhood; elementary; high school and higher; nonformal; lifelong learning	People with disabilities access education and lifelong learning, leading to fulfillment of potential, a sense of dignity and self-worth, and effective participation in society	To work with the education sector to help make education inclusive at all levels and to facilitate access to education and lifelong learning for people with disabilities
Livelihood	Skills development; self-employment; wage employment; financial services; social protection	People with disabilities gain a livelihood, have access to social protection measures, and are able to earn enough income to lead dignified lives and contribute economically to their families and communities	To facilitate access for people with disabilities and their families to acquiring skills, livelihood opportunities, enhanced participation in community life, and self-fulfillment
Social	Personal assistance; relationships (marriage and family); culture and arts; recreation, leisure, and sports; justice	People with disabilities have meaningful social roles and responsibilities in their families and communities and are treated as equal members of society	To work with all relevant stakeholders to ensure the full participation of people with disabilities in the social life of their families and communities. CBR programs can provide support and assistance to people with disabilities to enable them to access social opportunities and can challenge stigma and discrimination to bring about positive social change
Empowerment	Advocacy and communication; community mobilization; political participation; self-help groups; disabled people's organizations	People with disabilities and their family members make their own decisions and take responsibility for changing their lives and improving their communities	To contribute to the empowerment process by promoting, supporting, and facilitating the active involvement of people with disabilities and their families in issues that affect their lives

Source: World Health Organization (2015) shortcomings in terms of funding and trained personnel capable of making appropriate accommodations, especially in rural areas and small towns. The Ministry of Education is committed to making improvements, but this is a process that is going to take more time. Historically, Colombia has had a parallel and unequal educational system of private and public education in midsize and large towns. Most middle- and upper-income families send their children to private schools, while the public educational system is utilized primarily by lower, middle, and poor families. In order to attain the general goal of "education for all," it is imperative to establish cooperation between the communities and the educational sector. In this task, the local community schools play a critical role. The Ministry of Education is increasing its support of public schools in order to make them more inclusive. In large towns, there are a number of privately operated segregated schools for children with severe disabilities. The CBR approach seeks to join efforts to prevent exclusion and discrimination in the public schools, working in collaboration with the Ministry of Education, local school(s), communities, and families. The CBR emphasizes inclusive and accessible education with universal design in order to promote access to learning, where students can develop their potential, with an effective participation that meets the diversity of their needs and their rights, attempting to reduce barriers that hinder their right to learn.

Livelihood According to Correa-Montoya and Castro-Martínez (2016) and based on the 2005 census, of the approximate 3 million persons with disabilities in Colombia, 52.3% are adults in productive age (about 1.6 million people), but only 15.5% (480,000 persons) have a job, and just 2.5% reported earning the minimum salary or more (which is about 236 USD per month). A productive and well-remunerated job is essential for the social and economic integration of PWDs. A job offers income, self-esteem, a sense of belonging, and opportunities to contribute fully within one's community. It is essential that the programs related to CBR collaborate with the labor sector in order to guarantee that youth and adults with disabilities have access to training and job opportunities in the community. These development-oriented strategies intend to reduce the economic cost of disability by increasing the functionality of PWDs and reducing the barriers that limit their access to economic and social opportunities (Metts, 2004).

The labor sector promotes vocational development and access to employment opportunities and improved job conditions. Unfortunately, as mentioned in the introduction, a significant proportion of PWDs in Colombia are unemployed given the barriers to access and opportunities in the job market, the lack of awareness about their abilities, and their limited access to appropriate vocational training programs. Within the CBR framework, there is an emphasis on promoting vocational training to develop the skills and competencies of individuals with disabilities so they can become employed. Through the CBR strategy, PWDs and their families can have access to training processes and job opportunities that also opens their possibilities of access to livelihood programs and social protection in pursuit of a better quality of life in their familiar environments. There is also an urgent need to educate employers and the general public about the importance of offering employment opportunities to PWDs, their rights, the prejudice and misconceptions commonly held about PWDs, and their success in retaining jobs once they become employed. There are many barriers that remain in part because of a long history of assistance toward people with disabilities and the unemployment and underemployment rates.

Social Among the most frequently mentioned topics in this area are disability pensions, technical assistance devices, housing, and coordination with various service agencies in order to gain access to specialized services. This area can involve multiple community organizations, including religious, social clubs, sports, and many support groups. There are also NGOs both at the national and international levels that contribute to the development of the CBR framework. Some of the NGOs, particularly in the area of landmines removal, are making important contributions to the development of services and supports to individuals with disabilities in Colombia (see case story 1 and 2 from Handicap International). The CBR strategy fuels the public policy through mobilization, institutional agreements, and active participation of PWDs. In addition, many people with disabilities feel they are the only ones facing a particular problem, but when they meet people with similar problems, they may find that their problems are shared and that there are common solutions. Being together helps to minimize isolation and to increase mutual support.

Empowerment This is a process that requires developing a critical understanding of the social reality in which people live and the contextual forces that impact their lives (Balcazar, Suarez-Balcazar, Adames, Keys, Garcia-Ramirez, & Paloma, 2012). Change must start with people with disabilities shifting their mindset from being passive receivers to active contributors. This shift in thinking is important for overcoming the attitudinal, institutional, and physical barriers that may be present in the community. CBR programs can facilitate this process by raising awareness, providing information, building capacity, and encouraging participation, which can lead to greater control and decision-making. Awareness is the level of understanding that individuals have of themselves, their situation, and the society in which they live. Raising awareness assists people to recognize that there are opportunities for change if they become engaged in the process of pursuing such a change. The empowerment component turns the CBR into a strategy of exercise of human rights that drives the search for equal conditions for people with disabilities in a framework of social responsibility (WHO, 2010b). From this perspective, the CBR:

- Considers people with disabilities as subjects of law and not only of assistance
- Is itself a process of inclusion
- Is based on the principle of jointly responsible participation
- Contributes to decreasing attitudinal barriers, overcoming the invisibility of PWDs
- Allows the participation of PWDs in the decision-making process
- Does not impose actions that respond to a hierarchical order (MINSALUD, 2014c)

From its inception, the CBR framework is identified with the principles of the social movement of disability which question traditional assistance, denouncing the segregating nature of the asylums and emphasizing the need for inclusion of PWDs in society. The framework also promotes organizations of PWDs, which, based on the approach of rights and social justice, seek to exercise their citizenship and equal opportunities with others.

Disability Related to War

Colombia has been strongly affected by armed violence as a result of a conflict that has already lasted for over 50 years. Colombia has the second highest number of victims of antipersonnel landmines in the world—more than 10,000 in 25 years and more than 1000 of those victims were children (Human Rights Watch, 2007). Today, Colombia has 11,426 victims of antipersonnel landmines (Dirección Contra Minas Presidencia de la República, 2016, Minsalud, 2015).

Case Study 1: Meet Irma, the Landmine Survivor Turned Educator (Handicap International, 2015)

"It was very near our house, in a spot where we always went looking for wood," says Irma. "Suddenly, I stepped on something that exploded and caused a great cloud of dust. I was lying wounded on the ground screaming that I didn't want to die." Irma had stepped on a landmine—one of such countless devices planted in Colombia over the course of 50 years of conflict between the government, armed opposition groups, drug traffickers, and others. Irma survived the accident, but she would need lifelong care for her leg. During her treatment she was referred to Handicap International, which has supported Colombian landmine survivors since 1998.

Irma still struggles with memories of her accident and the challenges of being a single mother with a disability. Monica, a Handicap International mental health advisor, provides Irma with emotional support through regular counseling. “Sometimes I panic, when I don’t have money for food or nappies for my daughter,” says Irma. “Fortunately, Monica can calm me down with her good advice.” To help ensure others do not have to go through what she has gone through, she has become an ambassador and regularly visits people in their homes to raise awareness and give people the information they need to reduce the risk of accidents happening, “By helping others stay safe, something good has come from my loss.”

According to Handicap International (2016a), 80% of the survivors of armed violence have a disability, and landmines are an omnipresent feature of the conflict zones. The victims are primarily civilians from the poorest social classes, who live in the most remote and deprived areas in terms of health services. As a result of their injuries, these individuals are no longer able to work in their farms, forcing them to migrate to the larger urban areas in an often futile search for other employment opportunities. (Campaña Colombiana Contra Minas, 2016)

Colombia signed the Convention on the Prohibition of the Use, Stockpiling, Production and Transfer of Antipersonnel Mines and on their Destruction on December 3, 1997 (United Nations, 1997) and ratified it on September 6, 2000, and it entered into force on March 1, 2001. As part of this treaty, Colombia has thus committed itself to establish and enhance health-care services needed to respond to the immediate and ongoing medical needs of landmine victims, increase national physical rehabilitation services, develop capacities to meet the psychological and social support needs of landmine victims, actively support the socioeconomic reintegration of victims, ensure that national legal and policy frameworks effectively address the needs and fundamental human rights of landmine victims, develop or enhance national landmine victim data collection capacities, and ensure that in all victim assistance, emphasis is given to age and gender considerations (Human Rights Watch, 2007).

In 2011, the Colombian Congress approved the “Ley de víctimas y restitución de tierras No. 1448” (República de Colombia, 2011, June 10) that established a process for the integral assistance and reparation of victims of the internal armed conflict. This law articulates the rights of those individuals to access health-care, physical, and mental rehabilitation services and specifies a process humanitarian assistance (lump-sum payments) to facilitate community reintegration, since most of these individuals and their families were displaced by the war. The government seeks to address the needs of this population and coordinate the efforts of multiple agencies both public and private in order to guarantee the victims’ rights to justice and reparation. The law established a new Administrative Department of Social Inclusion and Reconciliation, which is in charge of providing direct services and attention to the victims, supporting their social and economic reintegration. Finally, the law also establishes a “Center for Historic Memory” responsible for compiling and recovering relevant materials and information—including testimonials from victims—in order to educate future generations of Colombians about the facts that led to the violation of the rights of the victims and the human consequences of the conflict. The law is based on the premise that in order to achieve prosperity, the country needs security, employment to help people overcome poverty, and integral reparation including restitution and rehabilitation, as well as assurances that the conflict will not be repeated.

One of the challenges of the law’s implementation is that the law establishes relatively short deadlines for applying for the benefits (request for assistance must be made within 1 year of the injury). Meeting this deadline can be difficult for survivors who are busy dealing with the consequences of their injuries, especially those who do not receive information about the reparation programs in the immediate aftermath of their injuries. (Ministerio De Trabajo, Republica de Colombia, Decreto 1352, 2013) According to Human Rights Watch (2007), many victims of antipersonnel mines end up applying for benefits when it is already too late to claim them.

On the other hand, the government of Colombia and the largest leftist guerrilla organization (Frente Armado Revolucionario de Colombia [FARC]) signed a comprehensive peace agreement in Habana, on August 24 2016, which is going to establish a policy for integral agrarian development reform, guarantees for political participation, an end of the armed conflict and a permanent cease fire, a program for substitution of illegal drug farming in territories formerly controlled by the FARC, and victims' reparations. This historical event is going to enhance the activities for removal of antipersonnel mines in the country and enhance opportunities for economic development in most of the areas affective by the armed conflict for many years.

Case Study 2: Flavio, from Landmine Victim to Pro Athlete (Handicap International, 2016b)

In 2000, Flavio lost his left leg after he stepped on a landmine in a field where he was working. The accident happened in Putumayo, a region plagued with conflict between armed opposition groups, the army, and criminal gangs. Several years after his accident, Flavio moved to Medellin seeking better care for his leg. "When I first arrived I was using a makeshift prosthesis that was held together with band aids and tape," says Flavio. "I got my current prosthetic leg from Handicap International. It is finally a proper prosthetic leg that allows me to be completely mobile." Then Handicap International Physical Therapist Yanrieth encouraged Flavio to start swimming as part of his rehabilitation. "Swimming made me feel better, both physically and mentally, and I gradually increased the intensity of my training," says Flavio. He is now competing to qualify for the 2016 Paralympics in swimming.

Recommendations to Service Delivery

The community-based rehabilitation process has many positive aspects, including the increase of social ties and solidarity among people with disabilities. In Colombia, this process has resulted in more positive attitudes toward people with disabilities, which has let them to increase their participation and contributions to the communities in which they live. Some families of children with disabilities are also aware of how the disability requires them to advocate for their children's rights.

The Colombian government prepared a report to the United Nations regarding its compliance with the Convention on the Rights of Individuals with Disabilities (República de Colombia Informe Inicial, 2013, June). Although Colombia has made significant progress with regard to the enactment of policies and laws that protect the rights of people with disabilities and conducted many activities to implement the CBR matrix guidelines, much work still remains. There is a big need to improve the institutional system of rehabilitation in order to provide better services and improve rehabilitation outcomes for people in need. (Ministerio de Trabajo, Republica de Colombia, 2016) The institutional rehabilitation process is still very deficient, outdated, and often only available in a few state capitals (Molina, et al., 2016). Even when CBR appears as a promising strategy to address the needs of many people with disabilities, barriers to implementation include:

- The need to increase funding for health, education, employment, and social services for people with disabilities who unfortunately have to compete with multiple national priorities, including the current investment in the

process of peace and reconciliation with the FARC guerrillas.
- The need to train professionals and service providers in ways that allow them to implement best practices in multiple areas of need, especially in isolated rural areas. Although there are many universities and even some that are designed to train people in remote areas through web-based learning, the quality of such programs tends to be poor.
- The need to invest resources to increase the accessibility of buildings, streets, and the transportation systems.
- The continued need to educate the general public about the importance of including people with disabilities at all levels of civil society, without pity and assistentialism approaches.
- The need to replace a deficit vision of disability with a resilience and empowerment approach.
- The need for the health system to provide appropriate psychosocial support for people involved in armed conflict situations.

In addition, a universal framework to enhance service delivery for all PWDs—regardless of the cause of the disability, particularly in the case of individuals who acquired their disability as a result of the armed conflict—is essential in order to avoid duplication of services and optimize resource utilization. With regard to the victims of war, some individuals become revictimized because they have to offer proof of having been assaulted, raped, injured, and/or traumatized. For most of the victims of violence, the humanitarian assistance is not enough. They often do not feel that money or a prosthesis will compensate for their losses. This is particularly true when the conditions have affected their health and their identity due to the fact that many have to move into refugee camps, they have to abandon their farming occupation, and their disability situation makes them, at least in the early stages of recovery, dependent on other family members.

A primary challenge for Colombia moving forward with the peace process is to influence public policies and strengthen community work to find and remove the thousands of landmines dispersed in rural areas, so people can come back to their normal activities. In many ways, international cooperation and NGOs' interventions have been extremely helpful to individuals affected by antipersonnel mines. However, those agencies cannot go beyond the humanitarian and emergency phases, and it is up to the Colombia government to develop the infrastructure to effectively serve the individuals in deed and address the problem of landmine removal.

Summary

Community-based rehabilitation can be an effective strategy to promote community efforts for increasing opportunities for individuals with disabilities that support their human rights, reduce their poverty, and enhance their integration. The World Health Organization, the International Work Office, and UNESCO highlighted the importance of:

1. The participation of people with disabilities in the planning and implementation of CBR programs.
2. The need for greater collaboration among the various government sectors that provide services to people with disabilities.
3. The need for local governments to support the implementation of CBR policies. Additionally, it seems that one of the most powerful impacts of CBR initiatives is on people's empowerment, so they become more aware of their rights and their need to be proactive in the pursue of their own rehabilitation and community inclusion goals. This is what makes them more engaged in taking steps related to their own life's projects.

The social commitment to the inclusion of people with disabilities must overcome multiple contextual barriers and the fear of exclusion of those who live with a disability. The value approach of CBR creates an important option for people with disabilities because of its objectives, its link to empowerment, and its focus on allowing individuals to access better occupational, educational, health/rehabilitation, and social opportunities. We believe that government entities, universities, corporations, NGOs, and people with disabilities' organizations can work together in Colombia to make the peace process real to all involved. They can take a proactive role in rebuilding the areas affected by the years of war. They can support the return of the hundreds of thousands of displaced families. They could become partners in creating a better future for all Colombians, especially for those with disabilities and the victims of war.

Learning Exercises

Self-Check Questions

1. What is community-based rehabilitation (CBR)?
2. What are the objectives of the CBR implementation in Colombian?
3. What were the most important conclusions after analyzing and systematizing the process of implementation of the CBR by the local health authority in the capital Bogotá?
4. Which first four areas relate to key personal needs, reflecting the multi-sectored approach of CBR?
5. How do you define empowerment of people with disabilities and how can this process operate in the context of CBR?

Experiential Exercises

1. Ask some of your colleges to simulate that you represent the Colombian government at the United Nations meeting in Geneva, about the CBR implementation in Colombia. The UN Committee on the Rights of Disabled People demands that Colombia adopt policies on rehabilitation and social inclusion of disabled people who have been victims of armed conflict. Can you make some recommendations? List at least three programs you could propose.
2. One of the big challenges for including PWDs in Colombian society is to change the common perception of them as victims and the stigma associated with it. Imagine that as an expert you have been asked to make a slogan for a public campaign to try to address the issue. What phrases would you propose to inspire Colombians to move toward a more inclusive society?
3. You are a journalist and need to write an article in a local newspaper about disability, CBR, and the armed conflict in Colombia. What would be your three main ideas for developing your article?

Multiple-Choice Questions

1. What is the highest level of education that Colombian disabled people reported?
   (a) Preschool
   (b) None
   (c) Primary school
   (d) High School
2. The National System of Disability (NSD) was established in Colombia as:
   (a) A set of normative rules and implementation guidelines
   (b) A series of guidelines, norms, activities, resources, programs, and institutions that allow for the formulation and implementation of disability public policy in the country
   (c) A complementary program for the implementation of policies referred to disabled people
   (d) A mandatory program for promoting the inclusion of disabled people in Colombia
3. The Colombian government adopted the definition of disability from the UNCRPWD (2006, December 6), which proposes that disability is:
   (a) A natural process of aging and dependency that is gradually experienced
   (b) A relation between the body and context in which people live
   (c) An illness that affects the process of self-care and autonomy
   (d) An evolving concept that results from the interaction between persons with impairments and attitudinal and environmental factors
4. The CBR model was established to:

   (a) Improve access to rehabilitation services for PWDs in low- and middle-income communities through the optimal use of local resources
   (b) Promote the rights for PWDs in isolated areas with several programs
   (c) Promote services for PWDs and their families
   (d) Improve health services in the rural areas
5. The CBR matrix is the framework that identifies the key areas and primary functions of interventions of the community-based rehabilitation approach. The five main life areas are:
   (a) Nutrition, security, education, housing, and freedom
   (b) Health, education, social services, family support, and income
   (c) Health, education, livelihood, social, and empowerment
   (d) Education, health, counseling, treatment, and social support
6. The characteristics of Colombian victims of war are:
   (a) The poorest social classes
   (b) Those who live in the most remote and deprived areas in terms of health structures
   (c) No longer able to work in their farms, forcing them to migrate to the larger urban areas
   (d) All the items
7. Bogota's report on CBR considers that a milestone for the development of the CBR is:
   (a) The Law 1618 of 2013
   (b) The enactment of the Convention on the Rights of Persons with Disabilities
   (c) The support offered by International NGOs
   (d) The research produced about CBR
8. CBR is an approach based on:
   (a) The Ecological Model
   (b) The Sociopolitical Model
   (c) The Activism Model
   (d) The Human Rights Model
9. A primary challenge for Colombia moving forward with the peace process is:
   (a) To deliver rehabilitation services for PWD and their families
   (b) To implement health services for all the Colombian population
   (c) To influence public policies and strengthen community work to find and remove the thousands of landmines dispersed in rural areas
   (d) To create programs based on community participation
10. Empowerment is defined as a process that:
   (a) Requires a set of cognitive resources
   (b) Requires a social capital that supports the process
   (c) Requires family support and training
   (d) Requires developing a critical understanding of the social reality in which people live and the contextual forces that impact their lives

Key

1-c
2-b
3-d
4-a
5-c
6-d
7-b
8-d
9-c
10-d

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Disability Policies and Practices in the Rural United Kingdom

24

Debra A. Harley, Allison R. Fleming, Sherri L. Greer,
and Patricia Mundt

Overview

The official name of the United Kingdom (UK) is the United Kingdom of Great Britain and Northern Ireland. The United Kingdom is located northwest of the European continent between the Atlantic Ocean and the North Sea. It has a total land area of 244,100 km^2, of which 99% is inland and the remainder inland water. The UK is comprised of four geographic regions – England, Scotland, Wales (which together make up Great Britain), and Northern Ireland. The capital of the UK is London. The people of the UK are called British; however, they have different nationalities (*Encyclopaedia Britannica*, 2016). The UK is one of the world's leading business locations and is one of the top ten manufacturers in the world. In addition, the UK has the largest industries in Europe for life sciences, the Incorporated Television Company (ICT), and the creative art industries (British Council, n.d.). The countryside ranges from green meadows and woodland to rugged moorland and mountains. The UK is a country with great geographical diversity. As such, it is not our intention to assume that the broad views expressed in this chapter are representative of the UK. Furthermore, it is beyond the scope of this chapter to include all areas of the UK; however, throughout this chapter, reference is made to specific regions of the UK.

According to the Department of Work and Pensions (2014), there are over 12 million people in the UK with disabilities, and approximately one in five people (19%) has at least one disability. This figure has remained relatively constant over time. The distribution of disability is fairly evenly spread across the UK. Across the EU member states, an estimated 25% of the population aged 16 and over have a disability. Aggregation of this percentage reveals the disability prevalence rate is lowest in Malta (12%), Sweden (16%), and Ireland (17%) and highest in Croatia (335), Slovakia (34%), and Slovenia (36%). The rate is 21.5% in the UK (Academic Network of European Disability Experts, 2013). Yet many people who have rights under the disability provision of the Equality Act do not consider themselves as having a disability (Heslop, 2013).

There is a consensus among unions, employers, insurers, and healthcare professionals regarding the need to improve rehabilitation in the UK (Department of Work and Pensions [DWP], 2004). The three main diagnostic or disability groups that

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D.A. Harley (✉)
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: dharl00@email.uky.edu

S.L. Greer • P. Mundt
ESDRC Department, University of Kentucky, Lexington, KY, USA

A.R. Fleming
Rehabilitation and Human Services, Pennsylvania State University, University Park, PA, USA

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account for the majority of sickness and invalidity (known as Supplemental Security Income and Social Security Disability Insurance in the USA) in the UK are musculoskeletal disorders, mental health disorders, and cardiorespiratory disorders (Gobelet & Franchignoni, n.d.). These three disorders account for approximately two-thirds of sickness absence, long-term incapacity, and ill-health retirement (disability) (Waddell & Aylward, 2005; Waddell & Burton, 2004). In fact, musculoskeletal conditions are a major cause of work absence and loss of work productivity in the UK (Black, 2008). Approximately 40% of people with rheumatoid arthritis (RA) stop working within 5 years of diagnosis (Young, Prouse, & Williams, 2009) because the onset of RA occurs most frequently at the prime employment age. However, people with mental health disorders, learning disabilities, or psychological impairments are less likely to be employed than are people with physical disabilities (Malo & Garcia-Serrano, 2001).

Healthcare coverage in the UK is universal. That is, "all those 'ordinary residents' in England are automatically entitled to health care that is largely free at the point of use through the National Health Service" (The Commonwealth Fund, 2016). Although healthcare has a key role in the treatment of illness and injuries, vocational rehabilitation also has a key impact in the outcomes of workers returning to work. According to Waddell, Burton, and Kendall (2013), "effective vocational rehabilitation depends on work-focused healthcare and accommodating workplace… Both are necessary: they are interdependent and must be coordinated" (pp. 5–6). Waddell et al. (2013) assert that "vocational rehabilitation should be a fundamental element of Government strategy to improve the health of working-age people" (p. 8).

Learning Objectives

By the end of this chapter, the reader should be able to:

1. Understand the general status of people with disabilities in the UK.
2. Compare legislation and government initiatives for people with disabilities of the UK and the USA.
3. Identify barriers to vocational rehabilitation services in the UK.
4. Identify cross-cultural implications of VR services for the UK.

Introduction

Vocational rehabilitation has many different definitions; however, the core principle is to engage individuals following injury or illness in a process of active change arriving at an improvement in functional ability and greater participation in society (British Society of Rehabilitation Medicine [BSRM], 2003). "In simple language, vocational rehabilitation is whatever helps someone with a health problem to stay at, return to and remain in work" (Waddell et al., 2013, p. 10). Work rehabilitation, also referred to as occupational rehabilitation and vocational rehabilitation, is defined by the UK Department of Work and Pensions (DWP) as "a process to overcome barriers an individual faces when accessing, remaining or returning to work following injury, illness, or impairment" (DWP, 2004, p. 3). Vocational rehabilitation is required both for people who become incapacitated during their working life (job retention) and for those with congenital or early-onset disabilities who require assistance initially to enter the employment market (BSRM, 2003). In the UK, vocational rehabilitation is influenced by multiple entities: charitable organizations, the Department for Education and Employment (DfEE), Department of Health (DOH), Department of Social Security (DSS), Department of Trade and Industry (DTI), and employers and their occupational health resources (BSRM, 2003).

The *Vocational Rehabilitation Standards of Practice* of the Vocational Rehabilitation Association (VRA) UK (2007) purports that several rehabilitation disciplines (e.g., medical, behavioral, vocational) and related process (e.g., case management, work adjustment, job placement) are linked within the central field, and an individual scope of practice may overlap with the central scope of vocational rehabilitation. Within the UK, "the VR professional is required to gain and maintain knowledge, education and professional experience for compliance with the Disability Discrimination Act (DDA) and specifically with reasonable adjustments" (p. 12). When services outside of the scope of practice of the VR professional are necessary, a clearly written justification for access to specialists is required.

Waddell et al. (2013) contend that key stakeholders need to understand the evidence-based aspects of vocational rehabilitation, specifically what works, for whom, and when. Furthermore, vocational rehabilitation is good business, is cost-effective, increases pathways to work and to return to work rate of benefit claimants, and should be underpinned by education to inform the public, health professionals, and employer about the value of work for health and recovery. The area in which more attention is needed regarding vocational rehabilitation is to improve interventions for mental health disorders, which are the largest and fastest-growing cause of long-term incapacity/disability in the UK (Waddell et al., 2013).

Rural services across multiple domains (e.g., healthcare, commerce, housing, transportation, police services) have been in steady decline over many decades, thereby reducing the ability of available organizations to a more basic level of service and a far smaller range of services than their urban counterparts. In addition, the challenges of services in rural areas are exacerbated by inadequate facilities; higher costs; socioeconomic, cultural, and political influences; and lack of counseling and related services for people with disabilities and their caretakers (Wood, 2004). Wood (2004) emphasized further "marginalization or social exclusion – hardship from low incomes, isolation, the lack of a secure home, difficulties reaching essential healthcare and services, powerlessness and the breakdown of social networks – may exist for groups of rural residents, either as a hidden or visible issue" (p. 10). Clearly, rural poverty has health implications for persons living in rural areas and further disadvantages those with disabilities.

In a comparison of health confidence in rural, suburban, and urban areas in the UK and the USA, Haven, Celaya, Pierson, Weisskopf, and MacKinnon (2013) found significant differences between the UK and the USA among residence types and between the two regions within residence types. Levels of health confidence were higher in the UK, and significant differences were found within regions in the USA, but not for the UK. The results of this study are consistent with earlier findings that the UK has one of the highest levels of patient satisfaction among European countries (Coulter & Jenkinson, 2005). Haven et al. suggested:

(a) Confidence in one's individual healthcare and the healthcare system may play a key role in influencing patients' utilization, assessment, and expressed desires regarding their health.
(b) Higher suburban confidence than urban and rural in the USA implies that factors in sub-

Research Box 24.1
See Haven et al. (2013).

Objective: This study aimed to determine whether self-reported confidence in healthcare differed between the UK and the USA, as well as by rurality or urbanicity.

Method: A secondary analysis was done of a subset of survey questions regarding self-reported confidence in healthcare from the 2010 Commonwealth Fund International Health Policy Survey. A telephone survey was conducted in participants from the UK and the USA. Participants consisted of 1511 UK residents (688 rural, 446 suburban, 372 urban, and 5 uncategorized) and 2501 US residents (536 rural, 1294 suburban, and 671 urban).

Results: Significant differences were found in self-reported confidence in healthcare between the UK and USA, among resident types and between the two regions within residence types. Reported levels were higher in the UK. Within regions, significant differences by resident type were found for the USA, but not for the UK. Within the USA, suburban respondents had the highest self-reported confidence in healthcare.

Conclusion: The findings warrant the examination of causes for relative confidence levels in healthcare between regions and among US residence types.

Questions:
1. What are the limitations of this study?
2. How could the definition of rurality have influenced the categories in the UK and the USA?
3. What additional variable would you examine, and how would you redesign this study?

urban resident settings may contribute to a sense of control or reliability.

(c) Lower confidence in rural Americans may be attributable to more than health insurance coverage and other factors such as income, race/ethnicity, age, and sociocultural factors (see Research Box 24.1).

Legislative Framework

The UK ratified the United Nations Convention on the Rights of Disabled People in July 2009. All UK government policies and practices must comply with the convention. The Office for Disability Issues (ODI) coordinates work on the convention on behalf of the UK government (Gov.UK, 2015). The key elements of vocational rehabilitation in the UK are identified as:

1. Assessment of functional, physical, psychological, and cognitive work capacity
2. Vocational assessment and counseling to determine suitable job options
3. Counseling to support adjustment to disability
4. Supervised on-the-job training and/or a short vocational course
5. Fitness and work conditioning programs
6. Confidence-building/self-esteem groups or individual sessions
7. Assessment of workplace suitability
8. Development of skills for job seeking
9. Brokerage and case management
10. Linkage with community-based agencies (Scottish Executive, Co-ordinated, Integrated and Fit for Purpose, 2007, p. 35)

Table 24.1 Relevant legislation

Health and Safety at Work Act (1974)
Sex Discrimination Act (1975)
Race Relations Act (1976)
Access to Medical Reports Act (1988)
Access to Health Records Act (1990)
Employment Rights Act (1996)
Data Protection Act (1998)
Human Rights Act (1998)
Disability Rights Commission Act (1999)
Race Relations (Amendment Act (2000))

Adapted from Barnes, Holmes, and the National Executive Committee of the College of Occupational Therapists Specialist Section – Work (2009) and Sayce and Boardman (2003)

In this section, several select pieces of legislation and government initiatives are discussed (see Table 24.1 for a list of other relevant legislations).

Disability Discrimination Act (DDA) of 1995 The DDA was extended in 2005. The key provisions of the DDA are (a) the definition of who meets the criteria of a disability; (b) protection from discrimination in employment; (c) protection from discrimination in the provision of goods, services, and facilities; and (d) protection from discrimination in education (Sayce & Boardman, 2003). Under the DDA, it is unlawful for organizations to discriminate (i.e., treat people with disabilities less favorably, for reasons related to their disability, without justification) in employment; access to goods, facilities, and services; managing, buying or renting land or property; and education. In addition, businesses must make *reasonable adjustments* (e.g., part-time work, mentor support, work in a different setting) to their policies or practices, or physical aspects of their premises, to avoid indirect discrimination. Initially, the act was relevant to employers with 15 or more employees. As of 2004, the provisions of the DDA are applicable to nearly all employers, not only those with 15 or more employees. Furthermore, the employment provisions of the DDA cover people with physical or mental impairments that have a substantial and long-term adverse effect on their ability to carry out activities of daily living. Finally, the act provides protection at the recruitment stage as well as for individuals already employed (Sayce & Boardman, 2003).

Status of People with Disabilities in the UK

According to Power and Power (2010), "people with disabilities represent a significant but often overlooked proportion of the British population" (p. 1). In 2012 and 2013, the most common impairments were mobility (57%), stamina/breathing/fatigue (38%), dexterity (28%), and mental health (16%) (Department for Work and Pensions, 2014). The prevalence of disabilities increases with age. According to the Department for Work and Pensions (2014), 7% of children had a disability compared to 16% of adults of working age and 43% of adults over the state pension age. The number of older people with disabilities is estimated to increase to 40% by 2020, if age-related disability rates remain constant (Institute for Public Policy Research, 2007). More women than men have disabilities in the UK. White ethnic groups are almost twice as likely as non-White ethnic groups to have chronic illness or disability (20% compared with 11%; Office of National Statistics, 2014). The occurrence of mental health-related illness is increasing, with estimates that one in four people will experience a mental health issue in any given year (Mind, 2009).

A consensus exists among unions, employers, insurers, and healthcare professionals regarding the need to improve rehabilitation in the UK (Department of Work and Pensions [DWP], 2004). The three main diagnostic or disability groups that account for the majority of sickness and invalidity (known as Supplemental Security Income [SSI] and Social Security Disability Insurance [SSDI] in the USA) in the UK are musculoskeletal disorders, mental health disorders, and cardiorespiratory disorders (Gobelet & Franchignoni, n.d.). These three disorders account for approximately two-thirds of sickness absence, long-term incapacity, and ill-health retirement (disability) (Waddell & Aylward, 2005: Waddell & Burton, 2004). In fact, musculoskeletal conditions are a major cause of work absence and loss of work productivity in the UK (Black, 2008). Approximately 40% of people with rheumatoid arthritis (RA) stop working within 5 years of diagnosis (Young et al., 2009), which is particularly problematic because the onset of RA occurs most frequently at the prime employment age. However, people with mental health disorders, learning disabilities, or psychological impairments are less likely to be employed than are people with physical disabilities (Malo & Garcia-Serrano, 2001).

People with disabilities are more likely to be unemployed, with the UK employment rate for working-age adults with disabilities being 49% compared to 81.8% for nondisabled people. Approximately 45% of working-age people with disabilities are economically inactive (The Annual Population Survey, 2013). Nineteen percent of households that include a person with a disability live in poverty compared to 14% of households without a person with a disability (Department for Work and Pensions, 2014). Of working-age adults with disabilities who are employed, the two most common accommodations are modified hours or days or reduced work hours and tax credits (Office of Disability Issues, 2011). The high rate of unemployment is the primary reason attributed to the observation that many people with disabilities are in low-income households. In addition, people with disabilities are disproportionately more likely to live in substandard housing; there is a shortage of housing that is architecturally or universally designed to meet the needs of people with disabilities (Department for Communities and Local Government, 2009). In fact, the majority of homes in England do not allow for access for someone using a wheelchair to enter the door without difficulty (Habinteg, 2014).

For people aged 25 to retirement with disabilities living in the UK, approximately one-third is living in low-income households (twice the rate of that for nondisabled adults). The low-income rate for those with disabilities of working-age adults is similar in 2008 but somewhat higher than in the mid-1990s. In addition, the proportion of economically inactive working-age adults who are in relative low income is higher in the UK than in any other EU country, and many of these people have disabilities (Department for Work and Pensions, 2014; Palmer, n.d.). Finally, people with disabilities in the UK identified challenging areas of their life to include health and well-being, money and benefits, leisure, and work and employment (Copestake, Sheikh, Johnston, and Bollen (2014).

In general, the situation for people with disabilities in the UK is characterized by the following:

1. Transportation barriers: pavement and road maintenance, access, and frequency of public transport are the major issues (Transport Research and Innovation Portal, n.d.).
2. Victimized by hate crimes (Home Office, 2014).
3. Reduced participation in the labor market in all European countries. At the EU level, about 47% of people with disabilities are employed, compared to 72% of nondisabled people. The average employment gap is 25% (Academic Network of European Disability Experts, 2013).
4. Higher risk of poverty compared to nondisabled people across all EU member states (Academic Network of European Disability Experts, 2013).
5. The majority of people with a disability acquire their disability later in life (Disability in the United Kingdom: Facts and Figures, 2014).
6. People with disabilities of state pension age are more likely than those of working age to report multiple impairments (Department for Work and Pensions, 2014).
7. People with disabilities of working age are more likely than those of state pension age to report problems with mental health disorders, learning disabilities, and social and behavioral impairments (Department for Work and Pensions, 2014).

For additional information and statistics on disability in the UK, see Disability in the United Kingdom 2014: *Facts and Figures* (2014) available at http://www.base-uk.org/sites/default/files/uk_disability_facts_and_figures_report_2014.pdf. The highest concentration rates of disability and number of life areas (e.g., education, leisure) in which participation is restricted are in the North East, Wales, the North West and East Midlands, which have higher numbers of residents defined as historically poor. This is largely due to a legacy of hard labor industries such as coal mining and shipbuilding (Office for National Statistics, 2013). The lowest rates of disability and restrictions of life areas are in London and the South East and the East England (Department for Work and Pensions, 2014). People living in Wales are most likely to have a limiting chronic illness or disability when compared to other regions of Great Britain (Office for National Statistics, 2013).

Disability and Geography Rural-urban classification defines areas as rural if they fall outside of settlements with more than 10,000 residents (GOV.UK, 2016a). The rate of disability in the UK varies according to geographic region. People with disabilities tend to be concentrated in poorer areas as a result of lower incomes and social allocation policy (OPDM, 2005). In addition to higher rates of disability within economically depressed areas, a general north-south divide with health in the North East is historically poor. A legacy of heavy industries (e.g., coal mining, shipbuilding), lifestyle choices, and other complex factors is attributed as the cause of such higher rates of disability in these areas (Office for National Statistics, 2013). According to the Department for Work and Pensions (2014), the distribution of people with disabilities is fairly even across the UK with the North East at 25%, Wales at 24%, the North West at 22%, and East Midlands at 22%. Conversely, London and the South East and the East of England have the lowest rates of disability at 14, 16, and 19%, respectively (Office of Disability Issues, 2011). However, residents of Wales are most likely to have a limiting chronic illness or disability when compared within other regions of Great Britain (Office of National Statistics, 2014). The areas with the highest proportions of people living with a limiting long-term health problem or disability are East Lindsey (26%), Blackpool (25.6%), and Tendring (25.5%), while the lowest levels are in Wandsworth (11.2%), Richmond upon Thames (11.5%), and the city of London (11.5%) (Office of National Statistics, 2013).

According to GOV.UK (2016b), the life expectancy is higher, infant mortality rate is lower, and potential years of life lost from common causes of premature death is lower in rural than urban areas. The most common cause of premature death in England is coronary heart disease, followed by cancer and stroke. However, individuals living in rural areas that are economically deprived and have poor health are in the greatest need and have the least opportunity to access services and "are hidden amongst scattered communities of the generally affluent and healthy" (Wood, 2004, p. 22). Although the health outcomes are more favorable for individuals living in rural than urban areas, this does not necessarily mean that they are healthier, rather potentially reflecting unmet need for services. Wood (2004) cautioned against the notion that "rural advantages" make rural areas healthier in which to live when, in fact, a succession of studies have questioned such a notion (p. 10). Furthermore, rural residents may be less likely to present with an illness and tend to seek help at a later stage of the development of an illness (Wood, 2004). Although rural populations face the same range of illnesses, health issues, lifestyle choices, and medical interventions as their urban counterparts, rural residents have fewer choices of primary healthcare providers and range of local services and are more likely to have to travel greater distance to access healthcare services. Unmet need due to service inaccessibility and poor geographical access is a problem in rural areas, presenting a challenge for rural service providers not only to measure needs more accurately but also to respond effectively (Wood, 2004).

Social Attitudes Toward People with Disabilities

The UK has made significant progress in integrating an anti-discrimination agenda into key areas of social life; however, attitudinal and structural change has been considerably slower (Pearson & Watson, 2007). Many people with disabilities in the UK frequently perceive that they do not have freedom of choice and autonomy over their daily lives. Furthermore, people in the general public believe that people with disabilities are less productive than nondisabled people and that people with disabilities need to be taken care of, suggesting a degree of "benevolent prejudice" exists toward people with disabilities (Office for Disability Issues, 2011). A survey by the Multiple Sclerosis Society (2012) found that British adults think people with disabilities need to accept unequal opportunity in their lives and believe individuals often overstate the level of their physical limitations. In both instances, men were more likely than women to hold these views.

Other perceptions of the general public toward people with disabilities in the UK revealed the following actions would positively affect attitudes toward people with disabilities: (a) greater presence of people with disabilities in daily life, (b) greater presence of people with disabilities in the workplace, (c) greater public discussion of issues facing people with disabilities, (d) people with disabilities and nondisabled children in integrated setting both inside and outside school, (e) more politicians with disabilities, and (f) more people with disabilities in the media (ComRes, 2011). Conversely, the following public attitudes would have negative effects on people with disabilities: (a) comedians making jokes about people with disabilities, (b) negative media coverage around people receiving disability benefits, (c) people claiming benefits when they do not have a disability, and (d) people using offensive language about people with disabilities (ComRes, 2011). Finally, people with disabilities had a lower engagement rate than nondisabled people in the arts and cultural sectors, in part due to physical barriers, lack of suitable transportation, and lack of communication devices at venues (Arts Council England, 2013; Office for Disability Issues, 2011).

Attitudes toward people with learning disabilities (LD) have become more favorable following greater emphasis on inclusion in educational and social settings in the UK. However, LD appears to be more stigmatized than physical and sensory disabilities but less so than mental health disorders (Scior & Werner, 2015). The fact that discrimination against people with LD is still an everyday reality is illustrated by high rates of unemployment and incidents of bullying and verbal abuse, physical harassment and violence, and hate crimes, seemingly for no reason other than appearing different and less able to defend themselves (Quarmby, 2008, 2011). Wilson and Scior (2015) examined implicit attitudes of adult UK residents toward people with intellectual/developmental disabilities (IDD) and also their association with emotional reactions and contact, which have previously been found to have a significant influence on attitudes and stigma. The results indicated implicit attitudes were not associated with explicit attitudes, social distance, or emotional reactions. Nevertheless, there were small to moderate associations between emotional reactions and explicit attitudes and social distance. Implicit attitudes did not vary according to participants' level of contact with individuals with IDD, type of the contact relationship (voluntary versus involuntary), gender, or educational attainment. Conversely, these participants' characteristics did affect explicit attitudes and social distance. Implicit attitudes toward individuals with IDD were somewhat negative and, unlike explicit attitudes and stigma, did not vary according to participant demographics or contact (Wilson & Scior, 2015).

Robinson, Martin, and Thompson (2007) examined attitudes toward and perceptions of disability of both people with disabilities and without disabilities. Participants were asked to respond to certain illnesses, conditions, impairments, and injuries and whether people were considered to have a disability. The following responses were perceptions of what constitutes a person having a disability: (a) using a wheelchair (91%), (b) blindness (87%), (c) severe arthritis (81%), (d) Down syndrome (71%), (e) schizophrenia (48%), (f) cancer (44%), (g) older person with hearing aid (44%), (h) severe depression (40%), (i) a broken leg (31%), (j) HIV/AIDS (27%), and (k) severe facial disfigurement (25%). Responses to these same conditions based on whether or not the respondent had a disability were as follows (for having a disability versus not having a disability): (a) 86 vs. 92%, (b) 83 vs. 88%, (c) 84 vs. 80%, (d) 64 vs. 72%, (e) 51 vs. 48%, (f) 56 vs. 41%, (g) 38 vs. 45%, (h) 49 vs. 38%, (i) 31 vs. 32%, (j) 32 vs. 26%, and (k) 28 vs. 25%. Understanding the implicit and explicit attitudes and perceptions held by people toward people with disabilities is important because both may have negative impact on the lives of people with disabilities (Wilson & Scior, 2015). See Table 24.2 for additional findings from Robinson et al. (2007).

In addition to the general social exclusion of people with disabilities, many do not participate in health- and social care because of receiving insufficient support, particularly from social care services, poor experiences of diagnosis/post-diagnosis support, and ineffective joining up between health- and social care services (Copestake et al., 2014). Copestake et al. assert that health inequalities cannot be addressed without tackling social inequalities. The experiences of people with disabilities in health and social care are punctuated by stigma and discrimination and create barriers for them in various spheres of life.

Barriers for People with Disabilities

In the UK, the law mandates accessibility to buildings and accommodation for people with disabilities. Although the law requires that all public service providers make "reasonable adjustments" to ensure their services are avail-

Table 24.2 Attitudes toward and perceptions of people with disabilities

A person who uses a wheelchair and a blind person are most frequently defined as having a disability
A person with HIV/AIDS and a person with a severe facial disfigurement are most frequently not seen as having a disability
Three-quarters perceived there has to be prejudice in society against people with disabilities
It was thought most prejudice exists against people with schizophrenia and HIV/AIDS
Respondents with disabilities consider there has to be slightly more prejudice in society against people with disabilities in general than nondisabled respondents
Most respondents felt comfortable with having contact with a person in a wheelchair, a blind person, or a person who cannot hear without a hearing aid
Respondents were least comfortable with people with mental health disorders
Generally, respondents would feel most comfortable with a person with a disability living next door and least comfortable with a disabled person marrying a close relative
Few respondents with disabilities reported violent, abusive, unfair, or unpleasant behavior
Where acts of violent, abusive, unfair, or unpleasant behavior had occurred, it was mostly on the street
Most respondents had not witnessed violent, abusive, unfair, or unpleasant behavior
Two-thirds of respondents with disabilities were confident with using public transportation
Respondents mostly thought that people in Britain do not think of people as getting in the way or with discomfort and awkwardness, over half the respondents thought that people in Britain thought people with disabilities need to be cared for, and over half thought that people in Britain thought they were the same as everyone else
Fewer respondents themselves thought people with disabilities got in the way and thought of them with discomfort and awkwardness than they thought people in Britain would think in that way
Respondents personally were more likely to think of people with disabilities as being needed to be cared for and more likely to think of them as the same than they thought people in Britain would think
No consistent views from respondents on whether people with disabilities should be expected to work rather than rely on benefits
Majority of respondents thought of people with disabilities as making just as good parents as nondisabled people
Most respondents thought that students with disabilities could do as well as nondisabled students
The majority of respondents thought that a person with a disability should not have to live in a residential home if they do not want to

Adapted from Robinson et al. (2007)

able to people with disabilities, the transportation section is an exception. The London Underground and the UK's national rail system are not readily accessible for people with disabilities. Moreover, public areas such as sidewalks may not be as accessible as well because many of them are narrow and uneven (Country Reports, 2017).

Higgins (2007) identified common barriers to rehabilitation in the UK to include the following:

1. Access to medical treatment due to extended National Health Service (NHS) waiting list
2. Economic factors – generous occupational sick pay or disability benefits
3. Lack of top-level organizational commitment
4. Costs of workplace modifications and availability of suitable alternative duties, particularly for smaller firms
5. Poor communication and lack of a common purpose among key stakeholders
6. Lack of coordinated approach among rehabilitation providers

An additional barrier is the inability of UK healthcare professionals, especially primary care, to initiate or refer for VR services as their clinical management and the provision of sickness certification may initiate prolonged absence from work (NHS, 2008). For example, rheumatologists and hospital-based therapists that focused on physical rehabilitation therapy did not recognize which patients could benefit from referral to a disability employment advisor and the subsequent support that can be offered to working patients (Gilworth, Haigh, Tennant, Chamberland, & Harvey, 2001). A similar barrier was found among UK community mental health teams (CMHTs) in supporting clients' vocational aspirations. Seebhom and Secker (2003) found CMHTs lacked knowledge about disability benefits or sufficient understanding about certain elements of interprofessional collaboration to enable clients to find and keep employment. The extent of concern was echoed by the Royal College of Psychiatrist, which asserted "CHMTs were ideally placed to take the lead in coordinating the vocational rehabilitation of those with psychiatric disorders, but lacked sufficient expertise in welfare advice and vocational work" (NHS, 2008, p. 15). Other barriers include inadequate access to and/or limited availability of health professionals, personnel's lack of skills to assist people with complex disabilities, and lack of collaboration between government and nongovernment organizations.

Despite increased physical integration, in general, people with disabilities, especially intellectual and developmental, remain socially excluded and vulnerable in the UK (Wilson & Scior, 2015). Since the adoption by the EU of the term social exclusion in the late 1980s, which was an effort to combat stigma attached to poverty and deprivation and subsequently to marginalization and unemployment, people with disabilities have continued to have restricted opportunities to participate in wider social and cultural activities (Rimmerman, 2013). Having sufficient choice and control over one's life is one of the key planks of government policy in the UK. Copestake et al. (2014) found people with disabilities in the UK have a long way to go to fill this aim. Limited self-confidence and self-advocacy interfere with some people with disabilities' capability to gain access to information about their rights or to engage in a legal battle when they are victims of discrimination (Gore & Parckar, 2010).

Government Initiatives to Enhance Opportunities for PWDs

In an effort to address some of these barriers faced by UK residents with disabilities, several programmatic initiatives have been developed, predominately in the areas of employment and return to work services. The following is a discussion of recent initiatives and a comparison to benefits and services that exist in the USA.

Pathways to Work (Pathways) Pathways to Work was originally introduced in 2003. The aim of Pathways is to assist incapacity claimants (PWDs) into, and toward, competitive employment (paid work). Pathways introduced mandatory work-focused interviews (WFI) with specialist incapacity benefit personal advisors (IBPA) and offer a range of services focusing on work and health, including the condition management program (CMP). The CMP provides assistance to customers (clients) to help them manage their health conditions. Services such as the New Deal for Disabled People (NDDP), Work-Based Learning for Adults (WBLA), Training for Work (TfW), and program centers were assembled into a coherent "choice package" that provides systemic work-focused support. In addition, payments have been added for those finding work to act as incentives. Jobcentre Plus is at the core of Pathways to Work. Initially, the mandatory program focused on individuals making a new or repeat claim for incapacity benefits (IB), but in 2005 it was extended to include individuals who had already been claiming IB for 1–3 years. Incapacity benefits is income support with a disability premium and is the UK's largest disability support program (Becker, Hayllar, & Wood, 2010). From a policy perspective, Pathways was initiated to (a) modernize disability policy with other twenty-first-century integration and self-sufficiency goals, (b) increase employment rates across the working-age populations, and (c) reduce the number of claimants receiving benefit (O' Day & Stapleton, 2008).

O' Day and Stapleton (2008) compare and contrast employment support and financial assistance programs for PWDs in the USA and the UK. First, both employment and financial assistance for PWDs in the USA lack the integration for programs in the UK. In the USA, the primary financial disability benefit program (i.e., SSI, SSDI) "require that a person, in essence, be unable to work to qualify for benefits, which limits return-to-work outcomes, and in part, explains why few people leave these programs' rolls" (p. 1). The SSI/DI eligibility focuses upon work limitations. In contrast, the UK's disability support system integrates employment support with financial assistance, especially for people claiming IB. Eligibility for IB is based upon a work capacity assessment that emphasizes a person's work abilities (O' Day & Stapleton). Secondly, the Pathways program integrates employment supports and IB by providing a series of mandatory supports geared to promote employment. Thirdly, universal healthcare is available in the UK. In the USA, universal healthcare is not an option; however, the Affordable Care Act has made subsidized healthcare coverage more readily available.

Employment and Support Allowance In 2008, the UK government implemented the Employment and Support Allowance (ESA), which replaced the IB program. The ESA is a benefit for people who are unable to work due to illness or disability. In comparison to the USA, ESA is the main UK's welfare benefit that provides financial support to individuals having difficulty finding and maintaining employment because of long-term illness or disability. There are two types of ESA. The first is contributed-based ESA in which an individual can receive if he or she has paid enough national insurance. It is a flat-rate benefit. Contributory ESA is not affected by any savings or other income, except for occupational or personal pensions. Unless an individual is placed in the *support group* (SG) (see Table 24.2), payment of contributory ESA will be limited to 12 months. Contribution-based ESA is taxable (AgeUK, 2015; Greaves, 2016). The second is income-related ESA, in which an individual can receive if he or she has no income or a low income. Payment into national insurance is not required nor is it taxable. Income-related ESA is a means-tested benefit. Income-related ESA is calculated based on an individual's needs, including those of a partner, and compared with the money the individual possesses, such as income and savings. Income-related ESA can be paid on its own (if the individual is not entitled to contributory ESA) or as a top-up to contributory ESA (if the individual is entitled). Income-related ESA can include amounts to help toward mortgage interest payments and some other housing cost. Unlike contributory ESA, income-related ESA is not time limited (Greaves, 2016) (Table 24.3).

The major change that accompanied the ESA program is the introduction of the work-related activity group (WRAG) and the support group (SG) for all claimants found not to be "fit for work" (FFW) (Morris, 2014). Morris explains the decision-making process for placement into WRAG and SG as follows:

> Decisions for the WRAG group are based on a score of 15 points or more against the functional descriptors described in the legislation. Those in the WRAG group may also have non-functional impairments, such as suffering from a life threatening disease that is seen as controllable or another recoverable medical condition. Placement in the SG, on the other hand, depends on the existence of a severe condition (e.g., chemotherapy, terminal illness, pregnancy risks, and those who meet functional criteria for severe physical or mental health risks, pp. 6–7).

Work Capacity Assessment (WCA) The WCA is the disability determination process that was

Table 24.3 Support group

If it is decided that an individual has a limited capacity for work-related activity, he or she will be placed in the support group of claimants. If placed in this group, the individual will not have to undertake work-related activities (although he or she can volunteer to do so if desired). The individual will receive a higher rate of ESA than claimants who are placed in the work-related activity group. If the individual is receiving contributory ESA, it can be paid indefinitely (as long as he or she continues to satisfy the conditions for it)

Adapted from Greaves (2016)

introduced in 2008 as an overhaul of the Great Britain disability benefit program. To determine whether an individual is too severely disabled to work, the Department for Work and Pensions has the individual complete a WCA. As part of the WCA, individuals may be asked to answer questions about how their disability affects their ability to work and to complete a medical assessment to determine how the condition affects their life and ability to work. If the individual is determined well enough to work, ESA is denied, and the individual has 1 month to appeal the decision. If ESA is approved, the individual will be placed in WRAG or SG (Greaves, 2016). A printable form of the guide for benefits and credits of ESA is available at https://www.gov.uk/employment-support-allowance/print.

New Deal for Disabled People (NDDP) The NDDP is the major program helping beneficiaries with disabilities (incapacity) get back into the workforce. It is a voluntary program where people with disabilities contact an approved job broker who works as a case manager to find suitable employment (in the USA, a similar model is Ticket to Work). The job broker has no involvement with VR but does assist with potential barriers to working such as mobility issues (NHS, 2008).

Legislation and government initiatives in the UK for people with disabilities are a response to inequalities. The intent is to identify the issues of people with disabilities as relevant and deserving of attention. Maintaining a focus on this population can help to improve the vocational rehabilitation service delivery system.

Vocational Rehabilitation Service Delivery System

Government officials and practitioners of various disciplines (e.g., rehabilitation specialist, occupational therapy) recognize VR does not occur in a vacuum. That is, the current VR environment in the UK reflects what is required of a working population, and as such work is deeply embedded in a political-economic-social context (Barnes et al., 2009). Barnes et al. suggest VR emphasizes having as many people working as possible as the goal, including removal of as many people of incapacity benefits and to create better working opportunities for people with disabilities. Suggested routes to help individuals back into work are through the same employer, different employer, or self-employment (Frank, 2016).

The traditional or medical model of rehabilitation is the dominant course in the UK. The traditional rehabilitation model consists of medical treatment, medical rehabilitation, vocational rehabilitation, and return to work or medical retirement (Waddell & Burton, 2004). The NHS rarely considers or provides vocational rehabilitation services (Waddell and Burton), even though early intervention is crucial in the 6 months before a person enters incapacity benefits, and once receiving incapacity benefits, individuals who receive it for 12 months stay on them for an average of 8 years (Chamberland & Frank, 2004). A pilot service, the Vocational Rehabilitation Service (VR service), which provided support for people with cancer, multiple sclerosis, and inflammatory bowel disease, was delivered between 2011 and 2014. The VR service had a target of engaging 160 clients. At the end of the pilot data, 303 people had used the VR service, 260 had been discharged, and 43 clients were still receiving support. The main referral sources were NHS and self-referrals. Self-referrals were signposted from a range of sources including health professionals. The case managers were successful in raising awareness of the service and encouraging health professionals to refer and signpost. Overall, clients and referrers evaluated the service model positively. The model offered (a) a tiered case management process, (b) specialist support with a strong focus on clients' work needs delivered by case managers who are vocational rehabilitation specialists, (c) client-led support, (d) open access with referrals accepted from a wide range of sources, and (e) links to other services to facilitate referral and signposting (McGregor, 2014).

In a review of the state of vocational rehabilitation in the UK, Frank and Thurgood (2006) concluded that close collaboration between the employment and health sectors is required to maintain an active and healthy workforce. Furthermore, to facilitate this collaboration, a group of trained health professionals is required. Greer (2011) contends allied health professionals (AHPs) are valuable in contributing to vocational rehabilitation in mental health services because they “have access to a range of models of practice and associated assessment and outcome measure tools which can support the development, implementation and evaluation of vocational rehabilitation practice” (p. 19). Models of vocational rehabilitation for mental health service users include supported employment, social firm (small business which provides support paid or unpaid work opportunities for individuals with mental health (MH) difficulties alongside other employees), clubhouse, transitional employment, supported education, and prevocational skills for work (Greer, 2011). According to Bond, Drake, and Becker (2008), evidence-based supported employment (EBSE) (e.g., individual placement and support model) is clearly demonstrated as the most effective means of supporting people with severe and enduring MH problems to gain and maintain employment. The enhancing the quality of life and independence of persons disabled by severe mental illness through supported employment (EQOLISE) project compared EBSE with other vocational rehabilitation services using prevocational models in six European countries and concluded the following: (a) EBSE clients were twice as likely to gain employment (55 vs. 28%) and worked significantly longer, (b) the total costs for EBSE were generally lower than standard services over the first 6 months, (c) clients who had worked for at least 1 month in the previous 5 years had better outcomes, and (d) individuals who gained employment had reduced hospitalization rates (Burns et al., 2007). Recent UK-MH policy recommends the use of EBSE as an important element of a comprehensive vocational rehabilitation service and centers of excellence (Greer, 2011, see p. 51–52 for a summary of key Scottish and UK policy relating to vocational rehabilitation and MH).

The social model emphasizes the societal barriers that people with disabilities face, rather than people having a disability because of their impairments. However, adhering to the social model does not mean ignoring these impairments because condition and impairment management is an important resource and part of life for people with disabilities (Copestake et al., 2014). However, Crawford (2012) asserts although the social model of disability has informed much of the research in the UK, evidence suggests this approach may not inform practice, particularly at the local level.

Table 24.4 Comparison of UK to other countries

USA
Assessment and rehabilitation have been, for many years, a more systematic and sophisticated process
Work samples and computerized occupational information are used extensively. There are several “systems” of work samples, of which Valpar and the key system are perhaps the most widely used in the UK. Valpar is rarely used against the standardized employment information of the American system
Rehabilitation (referred to as work preparation in the UK) is also more systematic in the USA. In the USA, it is called work adjustment, and an important part of the assessment (evaluation) process is to identify the “critical work behaviors,” which individuals may need to achieve their vocational aspirations and to determine whether there is a “shortfall” with regard to any of these
The USA has a much greater extent of proper professional training. Both rehabilitation counselors and vocational evaluators have their own professional organization, each with its own rigorous procedures for accreditation
The USA has several federal agencies (i.e., Rehabilitation Services Administration [RSA], National Institute on Disability, Independent Living, and Rehabilitation Research [NIDILRR]) with budgets that support personnel preparation, training, and research to develop new approaches in medical, social, and vocational rehabilitation
In the USA, rehabilitation facilities are accredited. This is done by the Commission on Accreditation of Rehabilitation Facilities (CARF), and much of the funding provided by the RSA is contingent on meeting CARF standards

(continued)

Table 24.4 (continued)

Evaluation standards and performance indicators for the state vocational rehabilitation services program seek to reflect the importance of placing the clients of rehabilitation programs not just in work but also in work that is matched to their abilities
Australia and New Zealand
Vocational rehabilitation services in both Australia and New Zealand are also based on a strong emphasis on professional training of staff. Each Australian state has a university-based, postgraduate training program in rehabilitation counseling. These receive financial support from the Commonwealth (federal) Rehabilitation Service, which has also commissioned from one university (Sydney), a distance-learning version of their program
Services in both Australia and New Zealand rejected the conservative approach to both policy and staffing that were once based on Beveridge-type assumptions. In both Australia and New Zealand, more radical changes were implemented service objectives and funding
The New Zealand solution was based on the introduction of a “no-fault” compensation scheme, one aim of which was to ensure cost containment through the earliest possible referral to rehabilitation (all types of medical, social, and employment rehabilitation). To implement that policy and program, rehabilitation *BSRM Working Party Report 59 International Perspectives Vocational Rehabilitation – The Way Forward*
Counselors were recruited and trained with a continuing commitment to the expansion and academic underpinning of research and development. In Australia, similar decisions were reached to replace the inherited UK model by more professional services. Workers’ Compensation Fund money was used to finance the development of new services
To reduce longer than necessary absence from work (and undue delay in referral for rehabilitation), a review of policy and services developed a radically different approach based on alternative principles. Early intervention to ensure earliest possible resumption of work after illness or injury required the timely availability of relevant services and their funding as well as an effective system of referral. To that end, new initiatives included the early review of all sickness absence, ensuring (in certain circumstances) mandatory referral for rehabilitation. To support that aim, it was necessary to: Invest significantly in the training of therapists and other relevant professions who would be involved in the provision of such services Stimulate a market in which those services were provided on a “fee-for-item” basis Create a new role for persons to work alongside patients in order to ensure proper assessment of need and delivery of services and to liaise with employers over return to work – the “case manager role”
Australia has also examined the feasibility of developing an occupational database, similar to that of the USA
Germany
In Germany, rehabilitation tends to be equated with vocational training. A countrywide network of centers exist, and they are extremely well resourced. Courses usually last 18 months and lead to a vocational qualification which is the same, in all respects, to that obtained by nondisabled people completing a more traditional apprenticeship training
Sweden
The Scandinavian countries – especially Sweden and Norway – have for some time pursued more “active labor market” policies, directed at getting people with disabilities back to work. New legislation has been introduced requiring employers “to submit a rehabilitation enquiry to the local insurance office within 8 weeks (of sickness absence).” It is also responsible for initiating and financing interventions aimed at work resumption, while the social security agency is responsible for the coordination and supervision of rehabilitation measures
Sickness absence in Sweden is certified by an occupational physician
The legislation mandates “firms to provide commensurate work to employees who have become disabled in their current jobs.” These mandates in principle are more far reaching than the mandates imposed on firms by the Americans with Disabilities Act in the USA
The Netherlands
There are a number of similarities between Sweden and Holland, including the provision of a partial disability benefit, which is however seldom realized in practice
For many years though, the very high numbers of people receiving disability benefits led to talk of the “Dutch disease.” Over the last two decades, the government has gradually tightened up its system, and now reference is sometimes made to the “Dutch miracle,” reflecting a relatively higher number of people returning to work
One particularly interesting feature of Dutch provision is the system, developed by the Joint Medical Service for matching job requirements to individual functional abilities and disabilities. The Joint Medical Service maintains an occupational database of around 10,000 jobs, and this is used to assess the extent of an individual’s disability – i.e., the loss of earnings arising from their disability – and thus the level of partial benefit needed. The database can also be used to help identify redeployment opportunities or new career possibilities

Adapted from British Society of Rehabilitation Medicine (2003)

International Perspectives

Over two decades ago, Floyd (1996) speculated that the UK might follow the USA in professional training and development of employment and vocational rehabilitation personnel. According to the British Society of Rehabilitation Medicine (BSRM, 2003), vocational rehabilitation has been taken very seriously in many other countries in contrast to the UK (see Table 24.4 for comparison to other countries). In comparison to the UK, vocational rehabilitation services and education and training for practitioners are much more developed in many countries, including the USA and Australia (NHS, 2008; Organization for Economic Co-operation and Development, OECD, 2003). For example, a small number of courses are available in varying format (e.g., degree, certificate, diploma, short courses) that addresses a range of levels of educational need. In addition, university and private providers offer specialist courses. In Scotland, however, provision of courses is limited (NHS, 2008). The BSRM suggests that other countries that have more effective rehabilitation services than the UK are countries that have invested resources into creating well-developed services, conducted assessment of the scale of demand for vocational rehabilitation services, hired staff with professional qualification, and are supported by an academic base for research. Rehabilitation facilities in the USA already have standards and regulations to follow (i.e., the Commission on Accreditation of Rehabilitation Facilities, CARF), providing service users and government officials with some idea of the standard of rehabilitation they might expect. Conversely, very few rehabilitation facilities have gone this route in the UK (Barnes et al., 2009).

Summary

People with disabilities in the UK face many challenges similar to those in the USA. Information on inequalities and discrimination is representative of the population with disabilities and does not distinguish significantly between those residing in rural and urban areas. Although the UK had implemented legislation to improve the quality of life of people with disabilities, many facets of healthcare delivery and social attitudes remain riddled with barriers. Furthermore, there is considerable variation by type of impairment. The remaining challenge for people with disabilities in the UK is for the public as a whole and service providers to have a better understanding of their medical, psychosocial, financial, and employment challenges.

Resources

Disability Discrimination Act of 1995 (c.50): http://www.equalrightstrust.org/ertdocumentbank//DDA1995.pdf
Office for Disability Issues: https://www.gov.uk/government/organisations/office-for-dosability-issues
Rehabilitation Council: http://www.rehabcouncil.org/uk
The European Blind Union: http://www.euroblind.org
United Kingdom Rehabilitation Council: http://www.rehabcouncil.org/uk
Vocational Rehabilitation Association UK: http://www.vra-uk.org

Learning Exercises

Self-Check Questions

1. How do vocational rehabilitation services in the UK compare to that of other countries?
2. What are the barriers to health and social care services in the UK for people with disabilities?
3. What are the distribution rates of disability based on geography in the UK?
4. How effective is the social model in addressing challenges for people with disabilities?
5. What are the key elements of vocational rehabilitation services in the UK?

Experiential Exercises

1. Conduct an interview or survey with a rehabilitation counselor in the UK to determine service delivery challenges and barriers.
2. Compare and contrast disability legislation in the UK and USA.

If given the opportunity to redesign the vocational rehabilitation system in the UK, what major recommendations would you make?

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Part IV

Rural Vocational Rehabilitation Practice and Service Delivery

25

Challenges After Natural Disaster for Rural Residents with Disabilities

Debra A. Harley, Lebogang Tiro,
and Maram Alfulayyih

Overview

Although this chapter focuses on natural disasters in the United States, we acknowledge disaster as a global phenomenon, and reference is made to international circumstances throughout. The long-term economic and social impacts of disasters often produce equally devastating consequences regardless of where they occur (Lynn, 2005). Disaster is the product of a combination of three elements: vulnerability, coping capacity, and hazard (United Nations Development Programme, 2004). Disasters generally are classified into two categories: natural (outside the control of humans) and technological breakdowns in human-made systems (International Federation of Red Cross and Red Crescent Societies, 2003; Quarantelli, 2003). Although hazards in themselves do not constitute disasters, natural hazards become a threat when they occur in an environment that pose a threat to human life, property, infrastructure, or the environment (Adebimpe, 2011). It is important to recognize that all disaster is local. That is, disaster has the greatest impact in the geographic area in which it occurs, resulting in physical, emotional, financial, cultural, and social devastation for those involved (Dass-Brailsford, 2008). The local impact of disaster involves "community-based planning that requires rehabilitation agencies play an active role in preparing their communities to respond to the functional needs of persons with disabilities before disaster occur" (Sprong, Lewis, Soldner, & Koch, 2011, p. 34). Moreover, Sprong et al. (2011) contend that as providers of services to PWDs, rehabilitation agencies are uniquely positioned to ensure an effective community-based response. In the event of the occurrence of disasters, emergencies, and other hazards, persons with disabilities face challenges in receiving timely response. Challenges, which are discussed later in this chapter, may be further exacerbated by functional limitations imposed by various demographic characteristics of PWDs (i.e., age and type of disability) for those in rural settings.

Naturally occurring disasters have a certain degree of historical predictability; however, the unknown factor is intensity due to climate destabilization (Hughbank & Cano, 2014) (see Chap. 33 for more information on weather and climate). Some natural disaster can be predicted and sufficient forewarning can be provided; nevertheless, history records that even when disasters are predictable, the outcome is still devastating. The lack of predictability means that most disasters will not have an immediate state or federal response,

D.A. Harley (✉)
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: dharl00@email.uky.edu

L. Tiro • M. Alfulayyih
ESDRC Department, University of Kentucky, Lexington, KY, USA

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and more recent experiences have told us that even with forewarning, communities must be prepared at the local level (USA Center for Rural Public Health Preparedness, 2007). Too often, the result for rural areas is ion in which known hazards are addressed reactively rather than proactively (Bryant, 2009). To most effectively meet the needs of RFT residents, with and without disabilities, emergency management and response require a coordinated effort involving both horizontal and vertical coordination at the local, state, and national level and integrative efforts (USA Center for Rural Public Health Preparedness, 2007). In any case, providing disaster and recovery services to PWDs in RFT communities may require rehabilitation counselors to not only address issues related to a disability but also early interventions to connect with support networks and community resources and concerns regarding primary traumatization, emotional and cognitive processes, and somatic behaviors. Understanding of the rural circumstances of PWDs can assist in understanding of the timeliness of recovery and the severity of impact (Adebimpe, 2011).

Learning Objectives

By the end of the chapter, the reader should be able to:

1. Identify the challenges of rural, emergency management.
2. Identify the challenges of disaster recovery for PWDs in RFT communities.
3. Identify disaster recovery challenges for persons with specific types of disabilities.
4. Understand the impact of poverty on disaster response and recovery in rural communities.
5. Understand counselor credentialing and competencies required for disaster recovery assistance of persons with disabilities.
6. Understand issues impacting counselors who engage in disaster recovery.

Introduction

All states, tribal areas, and US territories include rural, which has been defined throughout as potentially isolating locations (National Council on Disability, 2009). There are more than 8.6 million Americans living within rural, frontier, and territory (RFT) communities with disabilities (U.S. Census, 2014) for whom surviving and recovering from a disaster can be an enormous struggle. For those in RFT communities, the need for immediate and long-term response intervention becomes a matter of life and death. Too often meeting the needs of PWDs in the RFT areas in the event of natural disaster is cumbersome because of two human resource obstacles: (a) too few PWDs have insufficient disaster response officials trained to effectively manage the needs of PWDs; and (b) too few PWDs possess knowledge about disaster preparedness that could help save their lives (Blanck, 1995; Bright, 2013; Bryant, 2009). In addition, understanding what appropriate response methods should be implemented for PWDs during disaster remains problematic partly as a result of insufficient research validating best practices (National Council on Disability, 2009). Recommendations to overcome the aforementioned human resource obstacles would be to involve PWDs in the emergency preparedness planning as they are best equipped and most knowledgeable about the needs, circumstances, and functional limitations of PWDs for those residing in RFT areas. See Table 25.1 for resources for involving persons with disabilities in emergency planning.

The challenges of emergency management are different for rural communities in comparison to their urban counterpart and are categorized as (a) resource limitation, (b) separation and remoteness, (c) low population density, and (d) communication (Bryant, 2009). See Table 25.2 for rural challenges and limitations. Aside from the aforementioned challenges, lack of appropriate healthcare resources affects rural areas greater as a result of being geographically remote, often more than 20 miles from the nearest clinic or hospital (Davis, Wilson, Brock-Martin, Glover, & Svendsen, 2010). In addition, lack of transportation is often inadequate, a fundamental necessity for residents considering evacuation during emergency conditions. Unfortunately far too many PWDs in RFT communities do not have transportation (see Chap. 3 for discussion on

Table 25.1 Resources for involving persons with disabilities in emergency planning

ADA Best Practices Toolkit for State and Local Governments: http://ada.gov/pcatoolkit/toolkitmain.htm
American Association for People with Disabilities: http://www.aapd.ocm
American Association of the Deaf-Blind: http://www.aadb.org/information/emergency_parparation/emerg_plan.html
American Red Cross: People with Disabilities: http://www.redcross.org/prepare/location/home-family/disabilities
Disaster Resources for People with Disabilities and Emergency Managers: http://www.jik.com/disaster.html
Emergency Evacuation Preparedness Guide: http://www.cdihp.org/products.html#evac_guide
Federal Emergency Management Agency (FEMA): http://www.fema.gov/
National Organization on Disability: http://nod.org/disability_resources/emergency_preparedness_for_persons_with_disabilities/
Rehabilitation Engineering Research Center for Wellness Technologies: http://www.wirelessrerc.org/content/newsroom/guidelines-help-you-prepare-emergencies
Rehabilitation Engineering Research Center on Communication Enhancement: http://www.aac-rerc.com/
US Department of Homeland Security: http://www.dhs.gov/index.shtm

Table 25.2 Rural challenges and limitations of emergency management

Resource limitations – a lack of availability of capital, which includes human, financial, social, cultural, and political capital
Human capital is limited due to urbanization and out-migration of young, educated residents
Financial capital is concentrated in the assets of the remaining aging population and is lost to rural communities when urban heirs inherit and liquidate these assets
Social capital is relationship within and between emergency service agencies, community organizations, and local businesses. Rural communities are generally rich with social capital when almost everyone knows everyone else. Volunteerism is a rich source of social capital in rural communities
Cultural capital is the nonfinancial social assets, knowledge, and ideas of people that enable them to succeed
Political capital is the trust, goodwill, and influence a politician has with the public, community, and other politicians that has been built through the pursuit of popular policies
Separation and remoteness – the distance between residents. The remoteness of rural areas results in longer response time; thus, the "golden hour" to provide lifesaving trauma care is often expended well before rural residents reach urban treatment centers
Low population density – population size of the community or the number of people per square mile
Communication – public education about preparedness. Communication is more costly per person. In rural communities increased cost leads to reduced outreach prior to disaster and throughout an event
Equal access – equivalent resources that are considered essential and of the same quality in urban and rural areas

Adapted from Bryant (2009)

transportation). As previously discussed, remoteness of RFT communities adds to the difficulties of accessible and reliable communication technology during and following natural disasters. For instance, access to assistive technology (e.g., interpreters, TDD communication, signaling devices) for persons who are deaf or are hearing impaired is often lacking. Moreover, individuals with cognitive impairments (e.g., brain injury, Alzheimer's disease, developmental disabilities) may not have access to reliable assistance which is essential to cope with new surroundings and to minimize confusion factors (Blanck, 1995, n.d.). Equally as important is accessible and reliable rescue communications, which consists of a universal design approach to meeting the needs of persons with and without disabilities before and after a disaster (Blanck, 1995, n.d.).

National Disaster Recovery

The ability to recover from a natural disaster is highly dependent upon the level of preparedness before the occurrence of a disaster. There are federal guidelines to support state-level preparedness and response to disasters. Understanding the timeliness of response and following procedures is often the difference between safety and tragedy and life and death. In this section we identify several key national preparedness frameworks and organizations that provide guidelines for disaster recovery.

National Disaster Recovery Framework The *National Disaster Recovery Framework* (NDRF, 2016) was developed in response to the need to better understand the obstacles to disaster recovery and the challenges faced by communities seeking disaster assistance. The NDRF is a companion document to the *National Response Framework* (NRF, 2013). The NDRF is a guide to promote effective recovery, particularly for large-scale or catastrophic incidents. The NDRF provides guidance to support states, tribes, and local jurisdictions impacted by disaster. The "focus is on how best to restore, redevelop, and revitalize the health, social, economic, natural and environmental fabric of the community and build resilience" (NDRF, 2016, p. 1). The National Disaster Recovery Framework connects local, state, tribal, federal governments, private sectors, and nongovernmental and community organizations, which play vital roles in recovery. The NDRF has nine core principles (see Table 25.3) and is designed for ease of use for all individuals (with or without a disability) involved in disaster recovery.

The section of the NDRF on community considerations takes into account accessibility and recovery, ensuring inclusion of PWDs and rural

Table 25.3 Core principles of National Disaster Recovery Framework

Individual and family empowerment
Leadership and local primacy
Pre-disaster recovery planning
Partnerships and inclusiveness
Public information
Unity of effort
Timeliness and flexibility
Resilience and sustainability
Psychological and emotional recovery

Adapted from NDRF (2016)

recovery. For PWDs, issues related to children and adults with mental, physical, cognitive, intellectual, and sensory disabilities as well as others with access and functional needs are considered. Statutory and executive order obligations under the NDRF include accessibility in architecture, transportation, housing and effective communication, employment, education, policies, and programs including those receiving federal funding. Specific statutes and obligations are covered by the following:

- Robert T. Stafford Disaster Relief and Emergency Assistance Act (Stafford Act) of 1988, as amended (2013)
- Post-Katrina Emergency Management Reform Act; Rehabilitation Act of 1973, as amended
- Americans with Disabilities Act (ADA), as amended 2008
- Fair Housing Act of 1968, as mended
- Architectural Barriers Act of 1968
- Communications Act of 1934, as amended
- Individuals with Disabilities Act (IDEA) of 1975, as amended
- Title VI of the Civil Rights Act of 1964, as amended
- The Age Discrimination Act of 1975
- and Executive Order 13347, Individuals with Disabilities in Emergency Preparedness

National Preparedness Rural communities often need a pre-disaster regional recovery plan; however, they may lack the resources, leadership, or political autonomy to engage one. The NDRF permits for flexibility of recovery needs in rural areas. Because of logistical challenges, particular recovery needs following disaster may not only relate to people but to rehabilitation of land. Broadly defined, rehabilitation of land refers to returning the land to some degree to its former state. Land degradation from erosion (flooding) or fire may result in the land become unsustainable and unsuitable. A loss of land because of a natural disaster creates economic vulnerability to the region. Local, state, or federal agencies assist in rehabilitation of land through the provision of grant dollars, tax credits to rebuild, and other government programs. Distinctively, RFT areas' dependence on land (i.e., farming) results in disproportionate impact from natural disasters that require a recovery approach that is distinct from urban areas and manufacturing centers (NDRF, 2016).

National Response Framework The NRF guiding principles are engaged partnerships; tiered response; scalable, flexible, adaptable operational capacities; collaborative effort through unified command; and readiness to act. "The NRF is based on the concept of tiered response with an understanding that most incidents start at the local level, and as needs exceed resources and capabilities, additional local, state, and Federal assets are applied" (National Response Framework, 2013, p. 46). It is not a one-size-fits-all organizational construct, rather NRF emphasizes that response to incidents should be handled at the lowest jurisdictional level capable of handling the mission. The NRF uses the findings from the Strategic National Risk Assessment (SNRA) to construct and deliver the response core capabilities. The role of the SNRA is to identify the threats and hazards that pose the greatest risk to the nation. Specifically, risk threats identified by SNRA include natural hazards, a virulent strain of pandemic influenza, technological and accidental hazards, terrorist organizations and affiliates, and cyber attacks (NRF, 2013).

Red Cross Separate from both the NDRF and NRF, the American Red Cross has developed a booklet to assist PWDs and other special needs groups prepare for disaster (http://www.redcross.org/services/disaster/beprepared/disability.pdf). Although generic in nature, this booklet offers strategies that can be employed by PWDs in rural communities. Information include, for example, being informed, making a plan, assembling a kit, and maintaining a plan and kit. The Red Cross emphasizes being prepared means being equipped with the proper supplies that are needed in the event of an emergency or disaster. The recommendation is to keep supplies in an easy-to-carry emergency preparedness kit. Supplies include, for example, water, food batteries, medication, two-way radio, and first-aid kit. A more comprehensive list can be found at the Red Cross website at http://www.redcross.org/get-help/prepare-for-emergencies/be-re-cross-ready/get-a-kit. In conjunction with the Red Cross strategies, recommendations from other sources (i.e., listed in Table 25.1) can be used to improve pre-disaster preparation and recovery efforts that are specific to RFT communities. Beyond this, however, many of the recommendations of the Red Cross for disaster preparedness require PWDs to have adequate resources to obtain additional medications and supplies. Unfortunately, far too many PWDs in RFT communities do not have expendable income.

Rural Aspects of Social Vulnerability and Challenges of PWDs in RFT Communities

Often overlooked as mitigating factors of recovery from disaster for PWDs in RFT communities are poverty, vulnerability and health status, and disparities before and after a disaster in medically underserved communities (Davis et al., 2010; Lynn, 2005; Runkle, Brock-Martin, Karmaus, & Svendsen, 2012). Poverty is frequently defined and analyzed in terms of the lack of access to resources to sustain basic human capabilities of food, shelter, and safety (see Chap. 2 for additional information on poverty). Because of poverty, PWDs in RFT areas tend to have less than optimal healthcare coverage and have chronic health disparities leaving them at greater risk following a disaster. Vulnerability, in general, and disaster vulnerability, in particular, possess conceptual complexity for rural communities (Adebimpe, 2011). These vulnerable subgroups' (e.g., low-income, physical or mental disability, elderly, children, LGBTQ, and racial/ethnic minority populations) disability and chronic health needs of PWDs in RFT communities are often aggravated by, resulted from, and in some cases overlooked during response efforts (Runkle et al., 2012). According to Davis et al. (2010), "disasters themselves can catalyze new or exacerbate existent disparities in health and health care within the affected population" (p. 30).

Poverty Poverty as a social vulnerability in RFT communities is an area that warrants additional attention in the discussion of natural disasters. According to Lynn (2005), because of difficulty of accessing resources and decreased income, "a poor society is often vulnerable to natural disasters that contribute to keeping it poor over time" (p. 1). Burney, Simmonds, and Queeley (2007) echoed a similar sentiment regarding people living in poverty stating, "the capacity to survive and recover from the effects of a natural disaster depends on two major factors: the physical magnitude of the disaster and the socio-economic conditions of individuals or social groups who experience the crisis" (p. 1). The most vulnerable to natural disaster are the poor, children, and persons with disabilities. Moreover, the already impoverished poor, many of whom are persons with disabilities, experience worsen socioeconomic conditions after a disaster. Persons from rural areas who are impoverished are more impacted because of poverty, lack of private transportation, limited to no ability to pay for public transportation, and limited availability of public transportation. Unfortunately, the most impoverished are considered most at risk before and after a disaster (Burney et al., 2007; Fothergill & Peek, 2004) (see Chap. 2 for discussion on poverty).

Healthcare When disaster strikes, the healthcare system is immediately overwhelmed with injuries and acute illnesses during the initial stage, and long-term disabilities and chronic conditions may not be a priority. Moreover, as a vulnerable subgroup, PWDs are likely to receive inverse care (the people most in need of medical care are often the least likely to receive the care they need) in the weeks and months following a disaster (Davis et al., 2010). Often, acute illnesses occurring in the initial wave evolve into chronic health conditions or disabilities during the recovery phase of a disaster. From a public health perspective, Chandra and Aten (2012) suggested that the health status of people prior to a disaster is indicative of their status after a disaster. That is, healthy people are more resistant to illness and better able to survive disaster.

Housing/Shelter Sheltering is a major function of the response component of emergency management (Bright, 2013). "Shelter in place" suggests that often persons with special functional needs are served better by maintaining them in their own environment and providing supports to their location whenever possible. Sheltering in place for those living in poverty is difficult in RFT areas because their homes tend to be constructed of less durable materials and on unstable terrain. Isolation of many geographical locations is further hampered by lack of access to transportation. Relocation should be a consideration when it is not possible for individuals to safely remain in their location (Sprong et al., 2011). Service animals are included in sheltering, and owners will not only need to prepare evacuation supplies for themselves but for their service animals.

Resilience of Rural Communities Cutter, Burton, Christopher, and Emrich (2010) suggested the literature has divergent views on community resilience. Initially, the concept of resilience was applied to natural disaster to suggest resilience as the ability of a community to recover by means of its own resources (Mileti, 1999). Following, community resilience was viewed as a process linking the myriad of social capital and economic development adaptive capacities (Norris, Stevens, Pfefferbaum, Wyche, & Pfefferbaum, 2008). Eventually, Cutter et al. (2010) viewed "resilience as a set of capacities promoted through interventions and policies, which in turn help build and foster a community's ability to respond and recover from disasters" (p. 2).

Just as social factors are associated with risk following a disaster, so too is resilience. Resiliency can promote a sense of control, empowerment, and normalcy following disasters to ensure individuals are able to return to their community (Madrid, Grant, & Rosen, 2009). Madsen and O'Mallaun (2016) examined community resilience following a natural disaster in a rural town and found community resilience was associated with higher levels of social connectedness, optimistic acceptance, learning tolerance and patience, and learning from the past to prepare for the future. In addition, they concluded social capital forms a vital part of community resilience, and although resilience is tested only during times of adversity, social capital needs to be developed well prior to the anticipation of natural disasters. The ability of rural communities to recover after disaster lies in the capacity of rural emergency management to connect and collaborate prior to disasters. Collaborative activities are essential for resilience in rural communities to adapt to changes caused by disasters and the ability to maintain operations with enhanced processes geared toward future sustainability (Kapucu, Hawkins, & Rivera, 2013; National Research Council, 2009) (see Chap. 7 for discussion on resilience).

For people with and without disabilities, their ability to respond to disaster is dependent on the support structure surrounding them. People with disabilities may have coping and resilience contingencies in place depending on their situation. According to Jackson and Cook (1999), an individual with a disability may have developed an approach that confronts adversity directly. As such, these individuals have the experience of adjusting and adapting to the unique circumstances and barriers to their particular situation and can often adapt these coping skills and strategies to respond to the challenges of disaster recovery. There are, however, times when the support structure is also stressed, which increases the risk to the person with a disability (Jackson & Cook; Neria, Galea, & Norris, 2009; Sever, 2015).

Understanding Disability in the Context of Disaster Response and Recovery

The functional limitations of a person with a disability vary, are individualized, and depend on the type of disability. It is beyond the scope of this chapter to present a comprehensive view of the impact of disaster on all types of disabilities and their functional limitation. Thus, discussion is on what should be considered regarding the impact of disaster on PWDs in RFT communities. It is important to consider a person's emotions during a crisis in which he or she may experience feelings of fear, shock, or distress about the disruption because the disruption itself may not precipitate trauma (Brammer & MacDonald, 2002). Some people with physical disabilities must often make adaptations to their surrounding environment. Specifically, for those residing in rural areas, the environment may be more challenging as a result of a lack of accessibility (i.e., lack of sidewalks, soft shoulder on the side of roads, lack of public transportation). When an environment undergoes significant change due to disaster, adjustment of persons with physical disabilities can be greatly affected (Jackson & Cook, 1999). Additionally, mobility may become increasingly problematic as a result of limited functional capacity or lack of transportation. For individuals with mental health disorders, functional capacity is often affected adversely by the stress that accompanies disasters. However, some researchers suggest that mental health issues can be created through inadequate disaster response (Galea et al., 2007; Madrid et al., 2009). Typically, there is a need of surveillance of behaviors as well as injuries during the acute phase (usually 6- to 12-week post-disaster) that lead to mental health disorders. The limited availability of mental health services in RFT areas prior to a disaster is complicated further after occurrence of a disaster.

Njelesani, Clever, Tataryn, and Nixon (2012) indicated different groups of people with disabilities arise in disaster situations – people with newly acquired injuries and impairments, people with pre-existing disabilities, and people with pre-existing impairments. Persons with newly acquired disabilities are usually the first to be targeted and treated post-disaster, while persons with pre-existing disabilities suffer particularly high rates of mortality and morbidity from disasters, partially as a result of being less able to flee. Individuals in this group also experience greater loss of autonomy after disasters. Furthermore, persons with pre-existing impairments, depending on type, may have not found their condition to be particularly disabling prior to a disaster but more so after a disaster because of destruction of infrastructure. Individuals with chronic conditions (e.g., diabetes, HIV) face deterioration due to interrupted medical treatment (Njelesani et al., 2012). Let's consider the case of Bill and implications of his disability

Case Study of Bill

Bill is a 46-year-old, white male that resides in a rural town off the coast in South Carolina. Bill has diagnoses of diabetes, type II, with complications of early onset of vision loss and amputation of both legs. Also, he is diagnosed as being obese. Bill is no longer able to drive and depends on the paratransit system for transportation to and from his doctors' appointments. Bill was employed as a farmworker for 28 years. Currently, he receives SSDI. Bill dropped out of high school in the 10th grade. He does not have a GED.

Bill lives with his wife in tenet housing on a dirt road that is 5 miles from a highway. Although the house is inland, it is till close enough to the coastline and has the risk of flooding from hurricanes or excessive rainfall. His wife works as a housekeeper 3 days a week. She relies on a 1983 automobile that is less than reliable transportation.

Questions

1. What are Bill's functional limitations and capacities?
2. What issues need to be address in an evacuation plan for Bill and his wife?
3. During post-disaster recovery, what type of services is Bill in need of?

living in a rural area. Although the case of Bill is of a middle-aged man with multiple disabilities who lives in the south, similar implications for disaster recovery can also apply to someone with a disability in need of assistance due to a snowstorm in Montana, a tornado in Kansas, or a wildfire in Colorado.

An understanding of disability in the context of disaster response and recovery requires rehabilitation counseling professionals to consider immediate and long-term issues. Arguably, the complexities of disability in disaster consist of a person's abilities, functional limitations, and environmental barriers. Any one or combination of these factors might influence the post-disaster outcome of a person with a disability. Let's consider the case of a woman who is quadriplegic in her exchange with a worker to arrange transportation evacuation during Hurricane Katrina that is presented in Discussion Box 25.1.The case of Belinda is one with a tragic outcome. She lived in an urban area and was unable to evacuate because of functional limitations and barriers to transportation. In Belinda's situation, transportation never arrived. Others who were able to get to bus stops were faced with non-accessible and ill-equipped buses and were unable to evacuate. Although the outcome could not have been any more tragic, imagine the additional barriers Belinda would have experienced if she were living in a rural area. In either scenario the outcome is tragic.

Subsequent to the response and recovery actions of various agencies during and after Hurricanes Katrina and Rita, the National Council on Disability published reports on inadequacies found in response procedures and made recommendations for planning and responding to the needs of persons with disabilities in disasters. After centering on the immediate and short-term needs of PWDs, the shift has become focused toward long-term employment concerns of evacuees. At this stage, rehabilitation counselors assume their primary role and responsibility.

Discussion Box 25.1

[On August 29] Susan Daniels called me to enlist my help because her sister-in-law, a woman who is quadriplegic in New Orleans, had been unsuccessfully trying to evacuate to the Superdome for two days. …It was clear that this woman, Belinda Caixetta, was not being evacuated. I stayed on the phone with Belinda, for the most part of the day… She kept telling me she'd been calling for a ride to the Superdome since Saturday; but, despite promises, no one came. *The very same paratransit system that people cant' rely on in good weather is what was being relied on in the evacuation…* I was on the phone with Belinda when she told me, with panic in her voice "the water is rushing in". And then her phone went dead. We learned five days later that she had been found in her apartment dead, floating next to her wheelchair … *Belinda did not have to drown* [emphasis added].

Questions

1. What are the complexities of disability in the context of disaster for Belinda?
2. What do you think the outcome would have been if Belinda lived in a rural area?
3. Imagine yourself talking on the phone to Belinda. What would you have said?

Source: National Council on Disability (2006)

Role of the Rehabilitation Counselor

In working with people who have experienced natural disaster, counselors should consider several fundamental principles. Benveniste (n.d.) offers and identifies strategies for working with individuals traumatized in the immediate aftermath of a major disaster. First, counselors should take care of themselves and their colleagues, physically and emotionally (discussed later in this chapter). Secondly, counselors need to maintain clarity because it is easy to lose perspective and become confused in a crisis. It is best to slow down and discuss one's clinical decisions with colleagues. Third, the counselor may also find it useful to make a checklist of priorities to evaluate what is important from what is not. In working with clients, you should remember that for them safety, medical concerns, sleep, food, and shelter must be attended to before any psychological intervention can begin. Moreover, counselors should be aware that it is impossible for their clients may not overcome their fear until the real danger has been removed. Fourth, counselors need to collaborate and seek supervision from one another, as well as other service providers. Interdisciplinary interaction and consultation become essential for conscientious crisis intervention. Fifth, counselors need to understand that working with clients in crisis is not the same as seeing them in their office or clinical setting. The setting in which you deliver counseling after a disaster may be a large room with many other people performing various tasks or may not be a building at all. Clearly, confidentiality may be compromised by the nature of the emergency, the setting, and the need to consult with others. Finally, counselors need to be able to think or their feet. That is, they will need to improvise with resources, time, and space. They need to assess their task and choose goals appropriate to the circumstances and the situation. Keeping these strategies in mind, when working with clients in crisis, counselors must be able to strike a balance between working long hours and avoid getting overwhelmed and self-care.

Rehabilitation counselors may be called upon to serve as crisis counselors either in providing immediate or long-term counseling support to persons with disabilities regarding the traumatic event. It is important to note that in general rehabilitation counselors are not therapists or may not possess the credentials required to provide crisis intervention. Suitably trained, rehabilitation counselors can provide crisis counseling and refer to mental health specialists to undertake long-term counseling and treatment. Nevertheless, rehabilitation counselors should possess basic knowledge and skills regarding crisis and trauma response. Hughbank and Cano (2014) suggested that counselors may assume the role of a "roaming counselor" and provide that much needed face-to-face support at the crisis center, focusing on the person's immediate needs and then moving to the emotional needs. Once the initial response to a crisis event is over, it is when individuals of trauma will require counseling and support and resources and referrals to support agencies and mental health professionals. A distinction is made between disaster mental health and traditional mental health and rehabilitation counseling programs. Disaster crisis counseling is designed to address incident-specific stress reactions rather than ongoing or developmental mental health needs. Outreach and crisis counseling activities are at the core of crisis counseling (Jackson & Cook, 1999).

In some rural areas, ethnic minority groups make up a large portion of the population, while in other areas, they may represent a smaller concentration within a largely homogenous racial population. Thus, training on cultural sensitivity and competence may be required for counselors working in crisis intervention (Stone & Conley, 2004). Increasingly, immigrant farmworkers are becoming a larger concentration of ethnic minority groups in rural areas. In addition to awareness and sensitivity of ethnic minority groups, counselors should be aware of the season effect of the work and accessibility in rural cultures. According to Jackson and Cook (1999), apart from the normal phases people experience after a disaster, there are timing considerations in farming areas such as times of seeding, ground preparation, and harvest that typically offer reduced accessibility of outreach workers to those affected by disasters. Thus, counselors need to be aware not only of ethnic culture but also of geographical cultural (i.e., rural).

Another cultural perspective that counselors need to be aware of in the referral and counseling process of rural residents after disaster is the stigma associated with mental health in RFT communities. Although rural residents value face-to-face contact very highly, their cultural attitudes make it difficult for them to seek and engage in support services (National Rural Health Alliance, 2004). It is not as simple as the person walking through the door and requesting counseling services because he or she is experiencing PTSD or trauma after exposure to a disaster. The asking for mental health services may be more difficult for rural residents because of their independent and interdependent culture. It is therefore important to make contact through an outreach or community support, which they can accept. In addition to cultural stigma regarding mental health, rural residents tend to distrust outsiders and might be reluctant to seek assistance. And, within a cultural context, language and communication barriers may exist because of the person being non-English speaking or may have difficulty reading. If it is necessary to work with a translator, the counselor must consider how this dynamic may affect the way in which services are provided. The counselor is guided by a code of ethical conduct in this matter.

Counselors must also understand and respond to diversity within the population of people with disabilities, women, children, older adults, and other vulnerable populations and realize their responses to stress and stress-related disorders are quite different from that of others. When communicating with residents in rural communities, there is a need to consider terminology that is reflective of meaning and interpretation that is familiar to the area. Finally, rehabilitation counselors can benefit from knowledge of existing resources in the rural community. As expected, first responders are involved in crisis intervention and mental health professional in addressing mental and emotional consequences of disaster. However, the counselor needs to look beyond traditional crisis responders and personnel to those recognized as gatekeepers that are a vital part of the rural community's support system (e.g., clergy or churches, funeral directors, veterinarians, cooperative extension services) (Jackson & Cook, 1999).

Beyond the role of crisis counseling, the primary role of rehabilitation counselors is to assist persons with disabilities find employment and training opportunities. Frequently, natural disasters destroy places of employment. For persons with disabilities who were in the process of seeking employment when a disaster occurs, the counselor or employment specialist might lose contact with their client. In addition, clients who were already employed or in training might have become displaced. Much effort is devoted to reestablishing contact and resuming services. Rehabilitation counselors, however, should be aware that even after initial aftermath and recovery, clients might look to them for comprehensive services, especially in rural communities.

Standards for Disaster Crisis Counselors and Credentialing and Competence

Standards exist within the profession and educational training for counselor for responding to crisis and disaster. Jordan (2010) presents six general national/international standards that have been proposed for crisis counselors to use in responding to people and communities affected by disaster. The first is the need and capacity, which is dependent on the severity (i.e., loss and destruction) and duration of the disaster, the relief organization's capacity (i.e., funding, qualified crisis volunteers), and the local capacity (i.e., available mental health professionals, mental health facilities). The second standard is information gathering and initial assessment. This process includes the most vulnerable, at-risk population (e.g., persons with disabilities, older adults, children). Care should be taken to maintain confidentiality of information. The third standard is related to service delivery. Counselors are to be respectful of the culture, religious and spiritual values and beliefs, socioeconomic status, and history of the people with whom they are working. In addition, counselors are to provide impartial nondiscriminatory services according to the needs of the people affected by disaster. Standard four is process and outcome assessment. Process and outcome assessment help counselors identify emerging issues. Both should be done within the context of local culture, values, beliefs, and practices and also in the larger ecological perspective (e.g., historical, socioeconomic status). Standard five is counselor evaluation, which is to ensure accountability and to improve practice. The evaluation results are “lesson learned” for counselors and help the organization or agency in assessing what training, skills, and knowledge their counselors should have. The final standard is counselor skills and responsibility. Counselors require appropriate training, skills, and experience in traumatology, disaster mental health, and crisis counseling, as well as psychoeducational program delivery in which they learn how to assess their ability to function effectively in disaster-affected areas. This standard helps counselors to recognize signs of compassion fatigue, their own coping skills and resiliency, and previous history of trauma or present life cycle transitions (Jordan, 2010). Counselor can, and often times do, fall victim to emotionally charged stress (Hughbank & Cano, 2014).

The 2016 Standards of the Council for Accreditation of Counseling and Related Educational Programs (CACREP) require counselor education programs to offer coursework on understanding response to crisis, disaster, and trauma-causing events. Credentialing and cultural competence are interwoven aspects of providing services to RFT residents in recovery from disaster. Counselors are to follow their professional code of ethics or conduct and the six standards. Moreover, counselors should not practice beyond their skill level and scope of practice (Code of Professional Ethics for Rehabilitation Counselors, 2010; Jordan, 2010).

Counselor Self-care Issues

Counselors as service providers may be called upon to provide support and intervention to PWDs in the aftermath of natural disasters. In addition, counselors who themselves are residents of rural communities must be prepared to deal with disaster not only as a service provider but as a member of the community. Research suggests that human service providers and first responders are at risk for development of acute stress disorder, post-traumatic stress disorder (PTSD), and depression because of exposure to working in post-disaster areas (Fullerton, Ursano, & Wang, 2004). Post-traumatic stress disorder may occur within weeks of experiencing trauma or as long as years or decades later. “Despite a general trend for symptoms to occur after a traumatic event, then gradually abate, it is also important to note that there are a number of different trajectories the emergence of mental symptoms follow” (Harvey et al., 2015, p. 25). For example, delayed onset of PTSD was found in the 8-year follow-up of police officers responding to the World Trade Center attack; 9% were described as having a delayed onset of PTSD symptoms (Pietrzak et al., 2014). Similar results are seen in military members who were in combat. Experts declare that counselor self-care is essential in the midst of helping others in a crisis or after disaster situation (Benveniste, n.d.; Wehrman, 2010).

Gauthamadas (2005) asserted that disaster responders in all phases of disaster relief, including counselors, experience considerable demands to meet the needs of the survivors and the community. Typically, they are altruistic, compassionate, and dedicated people who occasionally have difficulty knowing when it is time to take a break from the recovery operation. Overwhelmingly, people who end up in the helping profession are more inclined to take care of others. The result is usually professional burnout. Other risk factors that counselors encounter during and after disaster recovery are presented in Table 25.4 and the manifestation of symptoms is in Table 25.5. Taking care of yourself or wellness is one of the critical assets of being a healthy counselor. To be an effective counselor, helping

Table 25.4 Risk factors for disaster recovery responders

Age – older people often fare better than their younger counterparts, in part, due to older relief responders having additional experience that serves as protective factors
Level of exposure – physical stress and fatigue and threat to life or other potential for harm
Lack of support
Perceived threat because of ethnicity and gender
Frustration in the ability to fulfill tasks that the counselor wants to undertake may be an added stressor (e.g., being unable to save lives)

Adapted from Gauthamadas (2005)

Table 25.5 Symptoms of stress in disaster relief responders

Psychological and emotional	*Cognitive*
Feeling heroic, invulnerable, euphoric	Memory problems
Denial	Disorientation
Anxiety and fear	Confusion
Worry about safety of self and others	Slowness of thinking and comprehension
Anger	Difficulty calculating, setting priorities,making decisions
Irritability	Poor concentration
Restlessness	Limited attention span
Sadness, grief, depression, moodiness	Loss of objectivity
Distressing dreams	Unable to stop thinking about the disaster
Guilt or "survivor guilt"	Blaming
Feeling overwhelmed, hopeless	
Feeling isolated, lost, or abandoned	
Apathy	
Identification with survivors	
Feeling numb	
Behavioral	*Somatic*
Change in activity	Physical exhaustion
Decreased efficiency and effectiveness	Exhaustion
Difficulty communicating	Loss of energy
Increased sense of humor	Gastrointestinal distress
Outbursts of anger, frequent arguments	Appetite disturbances
Inability to rest or "letdown"	Hypochondria
Change in eating habits	Sleep disorders
Change in sleeping patterns	Tremors
Change in patterns of intimacy, sexuality	Headaches
Change in job performance	Anxiety and nervousness
Periods of crying	Depression
Increased used of substances	
Social withdrawal, silence	
Vigilance about safety or environment	
Avoidance of activities or places that trigger memories	
Proneness to accidents	
Difficulty being close to others	

Adapted from American Counseling Association (2011), Gauthamadas (2005), and Zalaquett, Carrion, & Exum (2010)

yourself first is a principle that applies directly to all counseling professionals; if you are in need of care yourself, it is difficult to help others. Counselors who neglect their own mental, physical, and spiritual self-care are often replete of energy to assist others (Mursch, Swain, & Harding, 2007). In addition, the counseling process is a one-way encounter in which the counselor is offering empathy to the client, with no reciprocal return. In addition to burnout, counselors often encounter several other roadblocks to self-care: vicarious traumatization, compassion fatigue, and impairment. Vicarious traumatization or secondary traumatic stress is similar to PTSD in which counselors are affected by the trauma they hear about through clients. Compassion fatigue occurs when counselors experience exposure to the suffering of clients along with an inability to rescue them from the suffering results in feelings of depression, anxiety, depletion, or emotional withdrawal. Impairment occurs when the counselor demonstrates substantial negative functioning to the extent that it compromises client care or poses potential harm to the client (Shallcross, 2011). In fact, counselor impairment is a violation of ethical behavior. In order to remain an effective counselor to those affected by a disaster, awareness of and provision for one's own well-being need to be maintained throughout all phases of a disaster (Mursch et al., 2007).

Zalaquett et al. (2010) suggested group debriefing for counselors is important as it allows for an opportunity to share their experiences during the crisis and how it affected them. This process decreases the potential for isolation and behavior described in Table 25.5. Counselors should have a plan for individual and group self-care (because they are members of a team that provide services) (Wehrman, 2010). In fact, Hughbank and Cano (2014) recommended that all emergency recovery plans should include post-incident stress-related evaluations that will serve as a long-term mechanism to help ensure a more emotionally fit individual. It is important for counselors to know their personal limits, have a debriefing plan, and examine their own regular coping techniques used to decompress daily and determine if they are transferrable to the new setting or situation. Similar to working with residents of the community, interventions should be culturally appropriate and reflective of the counselor's worldview and cultural values.

Rehabilitation Agency Strategies to Minimize Service Disruption During and After Disaster

Because occurrence of natural disaster is inevitable, a degree of preplanning by agencies should occur. Too often a significant amount of confusion is present following disaster. Similar to the adaptive capacity of rural communities to sustain recovery at multiple levels (Kapucu et al., 2013), so too is sustainability an important element for rehabilitation counseling services in rural communities because preventive and intervention strategies and policies can reduce losses and minimize disruption of service. Immediately after a disaster, clients with disabilities continue to need vocational rehabilitation services and probably more so. The ability of rehabilitation agencies and counselors to meet the needs of clients will more likely be interrupted by disaster. Therefore, the question is how can disruption to vocational rehabilitation services be minimized during and after disaster? In this section, we discuss several recommendations for implementation.

First, planning should be an ongoing activity that includes input and support from multiple agencies. Both planning and responsibility should be based on partnerships and cooperation among public, private, and different levels of government and focus on strengthening networks among these interdependent segments to respond rapidly after disaster (Kapucu et al., 2013). Interagency cooperation becomes increasingly important because the effects of disasters and disruption to services are not confined to one particular agency. For example, agencies' personnel can facilitate information flow and provide consultation to professional colleagues across agencies. The intent is for agencies to be able to draw on a range of practices or services that may not originally be intended for them. Hurricane Katrina is an example of failure to have appropriate plans in place and coordination to maximize services for persons with disabilities, which resulted in significant loss of life (White, Fox, Rooney, & Cahill, 2007).

Second, the plan should be practiced annually. While a plan is the necessary first step, the plan is only as good as its implementation. Usually, rehabilitation counselors attend an annual statewide professional conference. An annual review of the plan and strategies can be a training session at that conference. In addition, conference organizers may also include a training session or preconference workshop by the state or local emergency management office. Once the initial training has occurred, it is crucial that there is ongoing staff awareness of the plan and strategies. Ongoing awareness and practice is necessary because during a crisis people tend to be agitated and confused because of a need to act immediately. Together, the planning and training processes offer a means of reducing some of the stress associated with disaster crisis.

Third, cross-training of human service personnel should be implemented at the state level. Various human service agencies can develop training materials and webinars to counselors, social workers, mental health professionals, cooperative extension personnel, healthcare staff, and so on as a statewide network for disaster recovery services for persons with disabilities. A network approach is feasible because rehabilitation counselors cannot be all things to all people all of the time.

Finally, post-disaster recovery is long term and has periods of progression and relapses.

Therefore, human service agencies should have interagency contingencies in place in which PWDs are able to initiate or reinitiate services at one of several agencies, especially one in close proximity to their resident. The intent is to have in place a service delivery continuum.

Summary

Persons with disabilities are at heightened risks during and after natural disasters. In addition, many persons with disabilities are further disadvantaged by post-disaster response. Risks are compounded where there are pre-existing barriers to persons' with disabilities full participation in the community. Risks are multiplied for residents with disabilities in RFT communities. Both persons with disabilities and RFT areas are vulnerable people and communities. Recovery from disaster in rural areas is an interdependent process; for the individual to recover, the community must recover and vice versa. Rehabilitation counselors can provide helpful consultation to and effective collaboration with other human service agencies and community supports in recovery efforts after disaster. Regardless of the amount of planning and level of networking, organizations require adequate resources to sustain their efforts of post-disaster recovery.

Resources

American Red Cross: http://www.redcross.org

Disability.gov's Guide to Emergency Preparedness and Disaster Recovery: https://www.disability.gov/resource/disability-govs-guide-energency-preparedness-disaster-recovery

Disaster and People with Disabilities (slide show) by David Alexander, University College, London. Available at http://www.slideshare.net/dealexander/disabled-people-in-disaster

Disaster Risk resilience Planning Network – Rural Disaster Resiliency Planning Tools: http://www.drrplan.net/node/141

Encyclopedia of natural Hazards. (2016). Switzerland: Springer International Publishing.

Federal Emergency Management Agency (FEMA): http://www.fema.gov

International Society of Physical and Rehabilitation Medicine: Rehabilitation Disaster Relief: http://www.isprm.org/collaborate/who-isprm/rehabilitation-disaster-relief

Learning Exercises
Self-Check Questions

1. Which type of activities lessen the severity and impact a potential disaster may have on rehabilitation services and community operations?
2. What is meant by emergency management and response require both horizontal and vertical coordination?
3. What are some challenges and limitation of emergency management in RFT areas?

Experiential Exercises

1. Review a disaster management and response plan to determine how it will be implemented in a RFT area and whether procedures are included for PWDs. If not, make some recommendations for accommodation of PWDs.
2. Develop a plan and protocol for counselor self-care for implementation in a post-disaster situation.
3. Interview a PWD to determine if he or she has a response plan to disaster. Identify and develop a resource manual for the individual. Be sure that the manual is in an available format.

Multiple-Choice Questions

1. Which of the following is helpful in meeting the communication needs of persons with and without disabilities before and after a disaster?
   (a) Social protocol
   (b) Universal design

   (c) Blanket communication
   (d) Dispatch radio
2. Which of the following is the focus of the National Disaster Recovery Framework?
   (a) How to best restore, develop, and revitalize the community to build resilience
   (b) How best to provide services in a cost-effective manner
   (c) How best to amend the Architectural Barriers Act of 1968
   (d) How best to require manufacturing centers to supplement disaster recovery
3. Which of the following is based on tiered response, scalable, flexible, and collaborative effort through unified command and readiness to act?
   (a) National Disaster Recovery Framework
   (b) Red Cross
   (c) National Response Framework
   (d) National Forrest Alliance
4. Which of the following affects the capacity to survive and recover from the effects of a natural disaster?
   (a) Physical magnitude of the disaster
   (b) Socioeconomic condition of individuals or social groups
   (c) Poverty
   (d) All of the above
   (e) None of the above
5. Illnesses occurring in the initial wave evolve into ______ during the recovery phase of a disaster.
   (a) Chronic and disabilities
   (b) Mental and dissolution conditions
   (c) Acute and chronic conditions
   (d) Transitory and disabilities
6. Which of the following is a presumption about people with disabilities' ability to respond to the challenges of disaster recovery?
   (a) Having the experience of adjusting and adapting to the unique circumstances and needs caused by their particular situation, they often are depleted and cannot adapt these coping skills and strategies to respond to disaster recovery.
   (b) Having the experience of adjusting and adapting to the unique circumstances and needs caused by their particular situation, they can often adapt these coping skills and strategies to respond to disaster.
   (c) Having been protected from adversities in life and discrimination because of their disability, they cannot adjust and cope with disaster recovery.
   (d) Having been emotionally challenged and having to adjust to a lack of accommodation, they choose not to exhibit resilience in response to recovery.
7. Which of the following is most likely to present barriers to people with disabilities who did not find their condition to be particularly disabling prior to a disaster but more so after a disaster?
   (a) Destruction of infrastructure
   (b) Loss of federal aid
   (c) A roaming counselor
   (d) Getting overwhelmed
8. Which of the following is designed to address incident-specific stress reactions rather than ongoing or developmental mental health needs?
   (a) Traditional mental health counseling
   (b) Rehabilitation counseling
   (c) Disaster crisis counseling
   (d) Cultural competence counseling
9. Which of the following organizations require counselor education programs to offer coursework on understanding response at crisis, disaster, and trauma-causing events?
   (a) Council or Rehabilitation Education
   (b) National Rehabilitation Association
   (c) American Association on Disaster Preparedness
   (d) Council for Accreditation of Counseling and Related Educational Programs
10. Which of the following best describes the recovery process from disaster in rural areas?
   (a) Independent
   (b) Resilient
   (c) Rehabilitative
   (d) Interdependent

Key

1. – B
2. – A
3. – C
4. – D
5. – C
6. – B
7. – A
8. – C
9. – D
10. – D

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Meeting the Needs of Rural Adults with Mental Illness and Dual Diagnoses

26

Debra A. Harley

Overview

The number of people with mental and brain disorders is a growing public health concern worldwide. Millions of people in the United States have a mental illness or disorder, and the number is increasing. Many people have diagnoses of more than one mental disorder at a time. Almost 45% of people with any mental disorder meet criteria for two or more disorders, with severity strongly related to comorbidity. Although mental disorders are common in the United States, it is those who experience disability due to serious mental illness (SMI) that are in greater need of services. The National Survey on Drug Use and Health (NSDUH) defined SMI as (a) a mental, behavioral, or emotional disorder (excluding developmental and substance use disorders), (b) diagnosable currently or within the past year, (c) of sufficient duration to meet diagnostic criteria specified within the 5th edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), and (d) resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities (Center for Behavioral Health Statistics and Quality, CBHSQ, 2015). In 2014, an estimated 9.8 million (4.2% of all US adults) adults aged 18 or older in the United States had a diagnosis of SMI, and 43.6% (18.1% of all US adults) had a diagnosis of any mental illness (AMI) (CBHSQ). The NSDUH defined AMI the same as SMI with the exception of resulting in serious functional impairment and limitations of major life activities. In addition, over 8.9 million people have co-occurring disorders – that is, they have both a mental and substance use disorder (Substance Abuse and Mental Health Services Administration, SAMHSA, 2015). According to the 2014 National Survey on Drug Use and Health, of the 43.6 million adults with some form of mental illness, 20.2 million adults (8.4%) had a substance use disorder, of which 7.9 million had co-occurring mental and substance use disorders.

Mental health (MH) and mental illness (MI) exist on a continuum, with no distinct line differentiating health from illness. The manifestation of mental illness varies with age, gender, race/ethnicity, and culture. Mental illness or disorder can range from short-term, situational depression to long-term chronic conditions such as bipolar disorder or schizophrenia (Gustafson, Preston, & Hudson, 2009). The most commonly diagnosed conditions are depression and anxiety disorders, which often are accompanied by substance use or addiction disorders (SAMHSA, 2015). In the United States, depression and major depressive disorders are the leading cause of disability for people aged 15 to 44 years, and almost 43% of persons with severe depressive symptoms reported serious difficulties in work, home, and social activities (Pratt & Brody, 2014). Depression is

D.A. Harley (✉)
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: dharl00@email.uky.edu

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associated with higher rates of chronic disease and increased healthcare utilization (Katon, 2003; Moussavi et al., 2007; Simon, 2001). Furthermore, mental healthcare is the most costly for people (National Council on Behavioral Health, 2015). Wang et al. (2005) found that the rates of treatment for depression often are low and the treatment received is inadequate. In an earlier study, Wang, Demler, and Kessler (2002) found predictors of not receiving minimally adequate treatment which included being a young adult or an African American, residing in the South, being diagnosed as having a psychotic disorder, and being treated in the general medical sector.

Research regarding the prevalence of mental illness in rural versus urban areas is inconclusive. On the one hand, research suggests that mental health disorders are no more prevalent in rural areas than in urban areas; however, they are different (Breslau, Marshall, Pincus, & Brown, 2014; Kiani, Tyrer, Hodgson, Berkin, & Bhaumik, 2013; Wang, 2004). Although Kiani et al. found no differences in the overall prevalence of mental illness by place of residence, they did find that autism spectrum disorder (ASD) was more common in people living in rural areas. On the other hand, research suggests that living in rural areas predisposes residents to risk factors because of lifestyle demands. Fraser et al. (2005) suggest that issues such as high poverty levels and occupational stress in rural areas often require different approaches and knowledge of how these issues and other community-related circumstances come to bare on residents' behavioral health. For example, farmers, farm workers, and their respective families face an array of stressors related to the physical environment, the structure of farming families, and the economic difficulties and uncertainties associated with farming which may be detrimental to their mental health (Fraser et al., 2005). Probst et al. (2006) found the prevalence of depression is slightly but significantly higher in rural residents compared to urban areas and possibly due to differing population characteristics. Yet again, other research suggests that urban living is long known to be a risk factor for psychiatric disorders such as major depression or schizophrenia (Adli, 2011; Schoevers, Beekman, and Dekker, 2010; Srivastava, 2009). Srivastava concluded that it is the impact of urbanization on people that move from rural areas to urban areas and the loss of social support of the nuclear family that brings the disadvantage of mental health problems. In Schoevers et al.'s study, the authors found significant correlation for prevalence of psychiatric disorders, mood disorders, and anxiety disorders and urban dwellers; however, they found no significant association for substance use disorders. Weich, Twigg, and Lewis (2005) found that rural residents had slightly better mental health than non-rural counterparts. However, the effects of geographic location on the mental health of participants were neither significantly confounded nor modified by socioeconomic status, employment status, or household income.

In this chapter, discussion is on the status of mental health disorders and dual diagnoses in RFT communities and is contextualized from the influence of rural culture on attitudes about mental illness and dual diagnoses, risk factors associated with mental illness and dual diagnoses, and barriers to treatment. The reader is reminded that attitudes toward MI and dual diagnoses vary among individuals, families, ethnicities, cultures, and countries and have numerous influences such as religion, cultural beliefs and practices, and geographical regions. Thus, the information presented in this chapter offers only a sample of various perspectives on MI and dual diagnoses. Throughout this chapter, the terms mental health disorders, mental illness, and behavioral health are used interchangeably.

Learning Objectives

By the end of this chapter, the reader should be able to:

1. Identify barriers to mental healthcare in rural areas.
2. Discuss risk factors for mental health disorders associated with living in rural communities.
3. Understand co-occurrence of mental illness and dual diagnoses.
4. Understand the economic and social costs of mental illness and dual diagnoses.

5. Identify approaches in which interagency collaboration can be implemented to assist persons with mental illness and dual diagnoses in rural areas.

Introduction

According to Kohn, Saxena, Levav, and Saraceno (2004), "mental disorders are not only highly prevalent medical conditions but they are also highly disabling" (p. 858). The effects of mental disorders also result in a high emotional toll on families and society. The treatment gap for mental disorders is universally large. In a review of community-based epidemiology studies using standardized diagnostic instruments and data on the percentage of individuals receiving care for mental disorders, Kohn et al. found the median treatment gap for schizophrenia, including non-affective psychosis, was 32.2%. For other disorders, the gap for depression was 56.3%, dysthymia 56.0%, bipolar disorder 50.2%, panic disorder 55.9%, generalized anxiety disorder 55.9%, and obsessive-compulsive disorder 57.3%. Alcohol abuse and dependence had the widest treatment gap at 78.1%. More recent data suggest that for some disorders, this gap is widening (National Institute of Mental Health, n.d.; Reeves et al., 2011). The consequences of lack of treatment include billions of dollars in lost earnings per year, increased hospitalization, earlier death age than others largely due to treatable medical conditions, and suicide (National Alliance of Mental Illness, 2015).

One of the goals of Healthy People 2020 is to "improve mental health through prevention and by ensuring access to appropriate, quality mental health services" (Office of Disease Prevention and Health Promotion, n.d.). The present status of mental health services in rural, frontier, and territory (RFT) areas is characterized as inadequate, overlooked, inaccessible, costly, and underfunded (Gustafson et al., 2009; Kessler, et al., 2004; Rural Health Information Hub, 2014; Sawyer, Gale, & Lambert, 2006). The most significant challenge to rural residents receiving care is the lack of mental health professionals providing mental health services in RFT areas (Mohatt, n.d.). Long-standing shortages of MH professional in rural areas have shifted much of the responsibility of care to the primary care sector or rural health clinics (RHCs) (Rural Health Clinic, 2009). In addition, RFT areas have greater numbers of suboptimal healthcare facilities.

The literature shows that RFT areas have unmet needs, numerous barriers to care, and serious problems with access to care in mental health services (Boyd et al., 2008; Costello, Copeland, Cowell, & Keller, 2007; Smalley et al., 2010) and substance abuse (Borders & Booth, 2007; Quinter et al., 2007; Quintero, Lilliott, & Willging, 2007). In light of evidence-based treatment focus, Gray (2011) advocates for a "major focus on the validation of assessments that are used to determine the efficacy of a treatment, testing various treatments within special populations, and examination of the cultural application of treatments" (p. 18). In addition, because of the mental health disparities and lack of mental health professionals in RFT regions, Gray emphasizes the importance of examining the quality of services provided by those trained as behavioral health aides, social workers, psychology technicians, counselors, and marriage and family therapists compared to psychologists (i.e., Ph.D.) and psychiatrists (i.e., M.D.). Finally, because rural residents are more likely to use pharmacology versus psychotherapy for treatment of MH disorders compared to urban residents (Ziller, Anderson, & Coburn, 2010), Gray calls for a closer look at prescription privileges for psychiatrists, use of psychiatric advance practice nurses, and physician assistants to address medication needs. Ziller et al., however, assert that the higher rate of pharmacology use for treatment of MH is not due to the client or patients' preference, instead because of the likelihood that they will receive treatment of mental illness from primary care physicians.

While healthcare professionals in rural areas are expected to deliver the most appropriate care to individuals with dual diagnosis, a substantial number of them have limited preparation and experience in working with clinical diagnosis issues (Deans & Soar, 2005). Initial levels of training for care providers, as well as subsequent training, continue to be a barrier to treatment services for residents in RFT communities. Deans and Soar imply that as a result of these limitations, professionals become frustrated, resentful, and powerless in their attempt to understand their client's substance use while simultaneously trying to provide a quality of mental health services.

Barriers to Mental Health Treatment in Rural Areas

Barriers are any processes, devices, obstacles, or circumstances that impede or prevent someone from gaining access to and using services or resources that is of benefit to them. Barriers to service occur for several reasons: (a) the environment (i.e., community acceptance or political will), (b) the clients themselves (i.e., noncompliance, culture), or (c) a lack of service coordination or service fragmentation (organization infrastructure) (Calloway, Fried, Johnsen, & Morrissey, 1999). For persons with mental illness and dual diagnoses in rural areas, these barriers are particularly problematic at the service coordination level because clients need to know both the "front door" (i.e., knowing where, when, and how to get services) and the "back door" (i.e., continuity of care and follow-up) (Calloway et al.). In rural communities, these barriers to treatment can be further complicated by rural culture attitudes or beliefs (e.g., you don't ask for help). The succeeding barriers are not presented in any particular order of importance.

Table 26.1 Barriers to the development of mental health services

Recruitment and retention – Difficulties recruiting mental health professionals due to chronic shortages of clinical social workers, psychologists, psychiatrists, or other clinicians in rural areas, as well as policies established by some payers restricting reimbursement to certain providers. Retention is difficult due to challenges of rural practice including professional isolation and professional boundary issues
Reimbursement – Poor reimbursement rates paid by Medicaid and commercial insurers, increases in patient co-pays and high deductibles
Administrative – Multiple third-party payers, inconsistent reimbursement and credentialing policies, managed care prior authorization requirements used to control utilization costs, and complex state licensure laws. These administrative requirements add costs on clinics and increase staff workload
Information and resource – Limited availability of RHC-specific resources and technical assistance in developing services

Adapted from Gale et al. (2010)

Availability More than 85% of rural residents live in a MH professional shortage area (Smalley et al., 2010). Gale, Loux, Shaw, and Hartley (2010) conducted a study to examine the changes in the delivery of MH services by RHCs, their operational characteristics, barriers to the development of services, and policy options to encourage more RHCs to deliver MH services. The study revealed that few rural independent providers and provider-based RHCs offer mental health services using doctoral-level psychologists and/or clinical social workers. The majority employed psychologists or clinical social workers on a part-time basis. The models used to provide services included contracted and/or employed clinicians colocated with primary care services. The participants in the study indicated that providing MH services in rural areas was challenging, and the majority reported they were not profitable. Gale et al. identified four barriers that plague RHCs in rural areas: recruitment and retention, reimbursement, administrative, and information and resource (see Table 26.1). In a study of rewards and barriers in rural areas, Allan, Crockett, Ball, Alston, and Whittenbury (2007) found that social workers experienced professional barriers, which had personal implications because they worked alone and because stress related to the seriousness of their client's issues had a significant impact on them. These social workers also felt professionally isolated, even as members of multidisciplinary teams because other team members do not often realize that social workers deal with situations that can have life or death consequences for very vulnerable people. Other barriers expressed included difficulty in accessing training, as well as the travel time and costs, and no financial rewards for the job, especially relative to the stress of the job.

Stigma and Culture "Public (social) stigma is a pervasive barrier that prevents individuals in the U.S. from engaging in mental health care" (Parcesepe & Cabassa, 2013, p. 1). In rural areas, social stigma in combination with a general lack of anonymity in small communities leads frequently to residents not seeking treatment (Gustafson et al., 2009). From a racial/ethnic perspective, Hispanics/Latinos tend to underutilize MH service and prefer to receive treatment from their primary care physicians. People of Asian backgrounds tend to reject MH services and rely more on family for support. African Americans tend to attach more of a stigma to mental illness and receiving services than Whites (Gamm, 2004). The research is limited on American Indians and Alaska Natives' views of mental illness; however, there is a general worldview that the mind, body, and spirit are connected and MI is an indication of a lack of balance. The degree to which stigma is attached to MI for AIANs is correlated with the level of deculturation from traditional beliefs and to the reculturation process that places them into the western health belief system (Grandbois, 2005). AIANs appear to use alternative therapies (e.g., spiritual healer, medicine man). The diversity of AIAN tribes does not allow for generalization of information about their views on MI. (See Chap. 3 for discussion on AIANs.)

In addition to cultural norms that regulate attitudes toward mental illness, rural residents must contend also with the traditional or conventional cultural belief systems that characterized rural communities (Letvak, 2002; Slama, 2004), as well as religious beliefs. Some rural residents may rely more on religion to cope with stress or believe that faith and prayer are sufficient forms of intervention. Rural residents may be concerned about seeking care of mental illness and substance abuse problems because of privacy concerns. Often, in RFT communities, the client seeking treatment may know the service providers and other workers within the treatment facility. In addition, clients may be concerned about other clients or patients noticing them utilizing mental health services and/or substance abuse treatment services. These concerns are further compounded by dual relationships, which may make people in rural areas reluctant to consult a mental health professional. (See Chap. 3 on dual relationships.) To help reduce these concerns, the Rural Health Information (RHI) Hub (2014) recommends collocation or integration of behavioral health services with primary care.

Fear and Distrust Fear of seeking mental health treatment is a barrier that is closely associated with culture, stigma, and shame. Overwhelmingly, RFT residents have a mistrust of mental health professionals (Russell, 2010; Sawyer et al., 2006). People find it difficult to reveal personal details to a counselor or doctor and have concern about "telling a stranger" about their problems (Susman, 2015). Racial/ethnic minorities' distrust may rest more in historical traumas and other economic and sociopolitical injustices. People recognize the negative stigma and discrimination associated with having a mental illness and do not want to be labeled as such. Many people fear that a label of mental illness could negatively impact their employment or career, education, or other life goals (Susman). Rural areas often have fewer and less diverse employment opportunities, and people fear that if knowledge of their mental illness were to become known, they may lose their job or not be considered for another job.

Costs Costs of care are another barrier to treatment in RFT communities. Although the Affordable Care Act (ACA) has increased access to healthcare for people, many rural residents cannot afford to pay for treatment or lack health insurance coverage. Gustafson et al. (2009) states that cost is perhaps the most pervasive barrier limiting access to mental healthcare services in rural America. Rural residents that are uninsured are more likely to delay or forgo treatment because of cost, especially Black, Hispanic, and American Indian rural adults. Rural populations have a larger proportion of low-income residents who could benefit from the ACA; however, almost two-third of uninsured rural residents live in a state, which has not expanded Medicaid. In addition, Hispanic/Latino adults in rural areas are most likely to be uninsured. Rural poor White residents are more likely to have insurance than poor rural racial/ethnic minority or other marginalized groups (Bennett, Olatosi, & Probst, 2008).

Other cost-related barriers include financing and reimbursement. According to Sawyer et al. (2006), these barriers range from uncertainty of public funding streams to funding systems that are complex and fragmented leading to increased costs for providers. More recently, the impact of payment assistance for MH services has been found to be a beneficial option for rural residents seeking mental health services in mental health treatment facilities. Payment assistance is offered in the form of no charge or a sliding-fee scale. Both of these options serve as a safety net for those individuals who need but cannot afford to pay for these services (Smith, Kuramoto-Crawford & Lynch, 2015). Although estimates of the number of MH facilities nationwide that provide MH services without charge or with some financial aid are not available, Smith et al. conducted a study to determine the availability of payment assistance for MH services in mental health facilities in the United States. They found that almost 9% of MH treatment facilities offered services with a sliding-fee scale, another 15.5% offered services at no charge only, and 42.7% offered both types of payment assistance. Approximately 20% offered neither type of payment assistance.

The availability of payment assistance also differed by type of treatment facility. Payment for assistance was offered in 88% of outpatient mental health center, 86.2% of multisetting mental health facilities, 76.6% of psychiatric hospitals, and 71.4% of general hospitals with separate psychiatric units. Among residential treatment centers (RTCs), 69% offered payment assistance for adults, and only 38% offered such assistance for children. Multisetting facilities provide outpatient and residential MH services and are not classified as a psychiatric or general hospital with a separate psychiatric unit or as RTCs (SAMHSA, 2014). Of those facilities that offered payment assistance, the majority (83–89%) provided either cognitive or behavioral therapy, individual psychotherapy, group therapy, and psychotropic medication therapy, and over half (56.7%) offered integrated dual disorders treatment (Smith et al.).

In the Smith et al. (2015) study, the availability of pay assistance varied by type of care facilities, facility operation, and whether the facility was located in an urban or rural area. Compared to urban facilities, rural areas had higher availability of a sliding-fee scale or free care. The higher rate of usage might be explained by Ziller et al. (2010) who suggest that the greater availability of payment assistance in rural settings coincides with higher rates of uninsured and underinsured persons in rural areas than in urban ones. Overall, children were least likely to be offered payment assistance. Thus, Smith et al. raised concern about the accessibility of service for children in need of residential care, especially since they have no way of paying for treatment. As a result, one can speculate that children who do not receive MH services will more than likely become adults with MI who do not receive services.

Budget Cuts Closely aligned with cost of services is budget cuts in mental health service funding by the states. In a review of states' budgets between 2009 and 2011, a report by Honberg, Diehl, Kimball, Gruttadaro, and Fitzpatrick (2011) for the National Alliance on Mental Illness (NAMI) found states cumulatively cut more than $1.8 billion from their budgets for services for children and adults living with mental illness. Although states differ in the way they report and break down of their budget information, the magnitude of cuts is staggering. Because of the magnitude of these cuts, Honberg et al. evaluated the cuts in two ways. First, they looked at the cuts in general funds (actual dollar amounts). The ten states that made the most cuts in general funds ranged from $587.4 million to $44.2 million. For example, in ascending order, the dollar amounts were California cut $587.4 million, Kentucky $193.7 million, New York $132 million, and Illinois $113.7 million. Second, Honberg et al. examined budgets to determine which states made the largest cuts by percentage of their overall state mental health general fund

Table 26.2 Principles of ACT

Primary provider of services. ACT specialists are highly trained and well-versed in all areas of treatment including substance abuse, mental health, and vocational skills. Their 1:10 ratio of professionals to patients ensures that persons receiving care get the most attentive treatment possible
Out-of-office treatment. Treatment occurs in the individual's home or a local community setting, such as a park or library
Individualized treatment. Each person is unique in his or her illness and/or addiction. ACT recognizes this and tailors treatment to each case
Long-term services. A person seeking treatment can do so anytime as staff members are available and understand that recovery is a lifelong commitment
Vocational expectations. Staff qualified in teaching vocational and life skills help a patient with job placement and employment opportunities
Psychoeducational services. Clients are taught about their illness and together with the provider work on ways to cope with the difficulties of severe mental disorders
Family support. Families are often impacted in ways we do not recognize. Providers educate families on the illness and offer support services to make dealing with it a little easier
Community integration. Because many patients with comorbidity are socially isolated or have trouble communicating, ACT professionals work with the individual on society integration to make them feel more comfortable in the community.

Adapted from http://www.dualdiagnosis.org

budget. Ten states made cuts ranging from 47% to 15%. Based on the second approach to viewing the budget cuts, three states from the first approach had made less than 15% of cuts, and three additional states were added. For example, in ascending order, the percentages of cuts were Kentucky cut 47.5%, South Carolina 22.7%, and Arizona 22.7% (Honberg et al.).

Given the amount of cuts in funding to treat MI, the question that is raised is, what do cuts of this magnitude mean in human terms? These consequences translate into frequent visits to emergency rooms, hospitalizations, homelessness, entanglement with juvenile and criminal justice systems, the loss of critical developmental years, premature deaths and suicides, and further diminished access to needed services (Honberg et al., 2011). In addition, the elimination or downsize of specific services are those that are most essential to helping persons who are living with serious mental illness to avoid crises and move forward. These include acute (emergency) and long-term hospital treatment; crisis intervention teams and crisis stabilization programs; targeted, intensive case management services; Assertive Community Treatment (ACT) programs (provides all-around care that focuses on more than the illness and addiction) (also known as assertive outreach, mobile treatment teams, continuous treatment teams, program of assertive community treatment, or other state-specific names) (see Table 26.2); supportive housing; targeted case management and clinical services for children and adolescents; and access to psychiatric medication (Honberg et al.). In rural areas, these cuts in MH funding come on top of already inadequate funding, with a largely uninsured and underinsured population, and at a time when the demand for MH services is increasing. These circumstances combine to create a national crisis. In the wake of budget cuts, a potential support for MH facilities in RFT communities is to seek grant funds from the US Department of Agriculture (USDA). In 2013, the USDA announced an investment goal to increase access to MH care in rural areas. The funds, which are provided through the Community Facilities Program authorized by the Consolidated Farm and Rural Development Act, can be used for construction expansion or equipping rural MH facilities. These funds can also help to expand and improve the services already offered by MH facilities in RFT communities (USDA, 2013).

Transportation, Isolation, and Inclement Weather Three circumstances converge to magnify barriers to mental health services in rural areas: isolation, inclement weather (see Chap. 33), and a lack of transportation. Rural residents are more likely to have to travel long distances to access healthcare, substance abuse treatment, and mental health services, particularly specialist services. In many cases, the roads and terrain are difficult and are made hazardous by inclement weather. Long distances to treatment, a lack of public transportation, and/or a lack of personal transportation all converge to make access to treatment challenging. (See Chap. 3 for information on transportation and accessibility.) Lack of transportation also creates potentially unsafe situations for individuals who travel to urban areas for MH services, such as when they are discharged from services in other communities with no method of returning home. In addition, travel to rural areas by MH service providers is a cost that community MH agencies have to absorb because travel costs are not considered in funding formulas or caseload benchmarks. As a result, community MH agencies must allocate a significant part of their resources (i.e., money and staff time) to transporting clients and providing outreach services (Canadian Mental Health Association, 2009).

Structural and Organizational Issues Often, a client or patient in the healthcare and mental health systems has to deal with multiple care providers across numerous specialty areas. During the process of healthcare services, there is insufficient communication among primary care providers and community mental health centers. The sharing of client or patient information is restricted by HIPAA (Health Insurance Portability and Accountability Act) or by incompatible software or hardware and inadequate infrastructure for telehealth connections. Frequently, there is lack of coordination among federal agencies, especially Health Rural Services Administration (HRSA) and Substance Abuse and Mental Health Services Administration (SAMHSA). In an era when external funding (i.e., grant funding) is necessary for organizations to continue or enhance services, many rural providers lack the organizational capacity or expertise. Sometimes, the barrier is that government agencies use urban criteria for contracts or grants (i.e., comprehensive rehabilitation programs). Furthermore, "resources have been concentrated in urban areas of the United States, and the limited availability, accessibility and acceptability of rural mental health and behavioral health services have created serious consequences for individuals, families, and state mental health authorities" (Sawyer et al., 2006, p. 8).

Some of these barriers are more problematic for mental health or substance use treatment, and others apply equally to medical care (National Alliance on Mental Health, 2015). The challenge that remains is to find feasible and enforceable strategies to remove barriers in RFT communities. The 2003 Presidential Commission report described the mental health system as "a 'patchwork relic' of disjointed state and federal agencies that frequently stepped in the way of people who were seeking care instead of helping them" (Russell, 2010, p. 30). The report called for the system to be more streamline, which focused strongly on early diagnosis and treatment in patients' own communities, to have high expectations of recovery, and to use methods for helping people with mental illnesses find work and housing. The report, however, did not recommend increased funding for mental health, rather for a more coordinated and efficient use of the money already available (Russell).

Risk Factors for Mental Illness in Rural Areas

Risk factors consist of socioeconomic conditions that can predispose or increase someone's vulnerability, thereby decreasing their ability to respond effectively to risks. In addition to the barriers previously discussed, rural residents are vulnerable because of less socioeconomic and social resources, less education, higher poverty, higher unemployment rates, inferior housing, higher rates of chronic disease, and less use of preventive health screening. Moore et al. (2005) suggest that rural residents, especially children, are not protected from biological and environmental factors that can cause MH problems. This suggests that even at a young age, residents of RFT areas are at risk for MI, and if left untreated, these disorders persist. Although lifestyle factors and behaviors are more important predictors of MI than remoteness per se, health-affecting behaviors are embedded in relationships between individuals and organizations, communities, families, and friends (Smith, Humphreys, & Wilson, 2008).

GeographicandIsolation-BasedFactors Generally, "geographic location and rural environments directly influence some aspects of the health status of rural populations" and "indirectly compound problems originating from more fundamental structural or social causes" (Smith et al., 2008, p. 57). The physical boundaries and geographic isolation impose a barrier to mental health accessing services and suicide prevention in rural areas. Lack of access to preventive or emergency care because of distance and a shortage of providers in mental health are also critical characteristics of suicide occurring in rural geographic locations (Hirsch & Cukrowicz, 2014). The more isolated and greater distance from urban areas, the more health deteriorates, including mental and physical health, higher rates of disability, lower life expectancy than the national average, and increased exposure to violence, poisoning, suicide, and accidental death (Haggarty, Ryan-Nicholls, & Java, 2010).

Protective Factors Protective factors are usually positive attributes or strengths that increase resiliency and enhance a group's survival strategies (see Chap. 7 for discussion on rural resilience). For many rural residents, the same protective factors (e.g., cultural identity, traditional health practices, family, rugged individualism) that function as strengths can simultaneously serve as risk factors and/or barriers to help seeking for MI disorders. For example, the belief and practice of being independent and solving one's problems without assistance from others, especially mental health professionals, often result in individuals not seeking help. Family members can hinder the client from seeking treatment if they also share these values. In addition, family members can interfere with the client's treatment because they fear the client may get better and no longer qualify for disability payments, which could change the financial situation of the family. This concern is especially so if the client's disability payment is the primary source of income for the family.

In contrast, Goodwin and Taha (2014) examined the association between being raised in a rural setting and physical and mental health among adults in the United States and found there are global health benefits of being raised in a rural setting (see Research Box 26.1). Goodwin and Taha asked a question to all participants about what sort of environment they were raised in for the majority of their childhood. However, what is not clear in their study is whether they asked if the participants lived the majority of their adult life in a rural setting. This raises the question of whether the results would have been different if a distinction was made between being raised (as a child) in a rural setting and living (as an adult) in a rural versus an urban setting. Other studies suggested that being born and raised in the same rural community is protective against developing mental disorders, whereas migrating between rural to an urban area or even migrating between rural environments may be a risk factor for developing psychological disorders (Maggi et al., 2010; Ostry, Maggi, Hershler, Chen, & Hertzman, 2010). Remaining in the same rural area provides adolescents and adults with an important sense of security and control that buffers against MI. Hirsch and Cukrowicz (2014) concur that capitalizing on protective characteristics of rural communities may be an important strategy to build upon.

Research Box 26.1: See Goodwin and Taha (2014)

Objective: To examine the association between being raised in a rural setting and physical and mental health among adults in the United States.

Method: Data were drawn from the National Comorbidity Survey ($n = 8098$), a household probability sample representative of adults aged 15–54 years in the United States. Multiple logistic regression analyses were used to determine the association between being raised in a rural area and the likelihood of mental disorders, physical disorders, suicide behavior, and parental mental health. Odds ratio (OR) with 95% confidence intervals was calculated, adjusting for differences in demographic characteristics.

Results: The sociodemographic characteristics of adults who were raised in a rural setting had a lower income, less formal education, more likely to be married, or formerly married, between the ages of 35 and 54 years old, male, and Caucasian compared to those who were not raised in a rural setting. Being raised in a rural setting was associated with decreased odds of ulcer. Mental disorders (any lifetime), any anxiety disorders, and any substance use disorders were significantly less likely among adults who were raised in a rural setting. Maternal psychopathology and exposure to trauma were significantly lower among those raised in a rural setting, compared with those who were not. These relations were not explained by sociodemographic differences.

Conclusion: These data provide preliminary evidence that being raised in a rural environment lowers the risk of mental and physical health problems in adulthood. Being raised in a rural community also appears to be associated with significantly lower likelihood of exposure to trauma and maternal psychopathology. Future studies can identify potential protective factors and mechanisms underlying these pathways are needed next.

Questions:

1. How might this data look differently if it were disaggregated by geographical region?
2. Given the limited diversity of the sample, what are the implications for racial/ethnic minority populations?
3. What other variable would you like to include in a study of this type?

Low Health Literacy Health literacy is the degree to which patients understand basic health information such as following instructions from healthcare providers, managing chronic illness, or taking medication properly (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Healthy People, 2010; RHI, 2016). Low health literacy is another risk factor for poor health outcomes in RFT communities. People with low health literacy have higher healthcare usage (i.e., more preventable hospital visits, greater use of the emergency room), are at greater risk of misunderstanding treatment recommendations, have problems in accurately taking prescription medications, and die earlier (Berkman, Sherdian, Donahue, Halpern, & Crotty, 2011; Vernon, Trujillo, Rosenbaum, & DeBuono, 2007). Those with low health literacy experience shame that may manifest as being intimidated of filling out forms, difficulty reading signs and locating places, and frequent medication errors. Unfortunately, medical staff and service providers may reinforce the shame experienced by individuals. Rural residents are at risk for low health literacy because they have lower educational levels as compared to residents in urban areas. For people in poverty and those with limited English proficiency, low health literacy is particularly problematic. Other common reasons for low health literacy include poorly developed materials and confusing instructions, learning disabilities, and a lack of frame of reference. People with chronic MI and/or physical health conditions are among those most likely to have low health literacy (Krishan, von Esenwein, & Druss, 2012). Schillinger (2011) asserts that vulnerable populations are at risk for health disparities not only because of their own literacy skills but also failure of health professionals to successfully communicate with patients who have limited health literacy regarding medication instruction, patient history, discussing symptoms and barriers to care in the absence of a physician eliciting it, and patient understanding of explanations and results and whether they ask questions. See Discussion Box 26.1 for an example of a prescription label that all patients are given regardless of their literacy level.

Discussion Box 26.1 Health Literacy

Professional Pharmacy

000 Main Street, Anywhere, USA 00000 (800) 000-0000

Caution: Federal law prohibits transfer of this drug to any person other than the patient for whom prescribed.

RX# 000-000-000 Dr. John Doe

Smith, John Date March 15, 2016

Take one tablet orally daily or every 6 to 8 hours as needed for symptoms

24 FazaClo Tab 10/500mg

No refills Clozapine Use before March 15, 2019

Do not take this drug if you become pregnant.

Do not drink alcoholic beverages when taking this medication.

May cause drowsiness or dizziness.

Discussion Questions

Presented above is an example of prescription label on a bottle of medication. Imagine a person with a low literacy level having to read this label.

1. Can you identify what each line on this label means?
2. What other information should come with this prescription?
3. What are some problems encountered by a person with a low literacy level?

Race/Ethnicity Some racial/ethnic minority groups are at increased risk for mental illness or dual diagnoses not because of their racial or ethnic identity but because of economic and social circumstances that put them at risk. In addition, the location of MH services might add to the potential for risk. For example, the availability of MH services is limited by the rural, isolated location of many AIAN communities. In addition, for AIANs, most clinics and hospitals for the Indian Health Service are located on reservations, yet the majority of American Indians no longer reside on reservations (American Psychological Association, 2010). AIANs have a historical precedent of alcohol abuse since the introduction of alcohol by frontiersmen and explores early in colonial history. "High rates of alcohol abuse in Indian Country are coupled with similarly high rates drug abuse" (p. 8). The rate of methamphetamine use in Indian country is over three times the rate of the general population (Iritani, Dion Hallfors, & Bauer, 2007). In fact, Jefferson Keel of the National Congress of American Indians believes "the destruction caused by methamphetamine threatens to dwarf the problems we have seen caused by alcohol" (cited in Indian Health Service, 2011, p. 9).

What constitutes mental illness or mental health is subject to many different interpretations and varies across racial/ethnic groups and cultures. In many racial/ethnic minority populations, MI is not seen as something that is wrong with the individual but rather more of society's effect on the individual. As such, MI is not viewed as pathological. Moreover, an individual is accepted within the community, and others recognized him or her as being a little different but not perceived as a danger to anyone. Cultural perceptions or misperceptions about MI can be as much a risk factor as other social risks (Dixon & Vaz, 2005).

Poverty The link between poverty and MI is well known (McGovern, 2014). Once an individual becomes incapacitated, his or her socioeconomic status is likely to decline further (Tiffin, Pearce, & Parker, 2005). In Australia, the United Kingdom, and the United States, four in ten people with severe mental disorder live in households with incomes below the low-income threshold, and the proportion is almost as high in other countries (Organization for Economic Co-operation and Development, OECD, 2012). Low educational level is linked to poverty. Ethnic minorities, older patients, and less-educated patients are more likely to have treatment disparities and to receive lower-quality care than other patients (Ahn et al., 2008). Each of these groups is overrepresented in poverty status, and rural residents have higher rates of poverty compared to their urban counterparts. Rates of hospitalization for psychiatric conditions are 44% higher for people in poor communities than in nonpoor ones and twice as high for poor people with schizophrenia (Healthcare Cost and Utilization Project, HCUP, 2008). Amoran, Lawoyin, and Oni (2005) found unemployment and living conditions below average, physical health, and large family size were associated with increased risk for psychiatric morbidity for rural populations.

Lack of Quality of Care The majority of primary care physicians express confidence in their ability to manage mental health problems; however, they do not always provide evidence-based care. (See Chap. 38 for discussion on evidence-based practices.) Primary care providers are often the first and only resource for RFT residents needing mental healthcare. Training on MH issues is not easily accessible for primary care providers in rural areas (McFaul, Mohatt, Ciarlo, & Westfall, 2009). As previously stated, primary care physicians in rural areas tend to overprescribe or, at least, rely heavily on medications (e.g., antidepressants) as the treatment of choice for mental disorders. Often, the dosage is not appropriate and the requisite follow-up visits are not always scheduled nor is psychotherapy included or always available (Russell, 2010). Russell stressed that it is not sufficient to simply improve the level of diagnosis of mental disorders; more must be done to ensure that patients receive beneficial, evidence-based therapy. While there is evidence showing that psychotherapy (e.g., cognitive behavioral therapy) is one of the primary treatment modalities for mental disorders, there are no training, licensure, or certification requirements obligating providers to have competence in such therapies. Also, there is usually no systematic way for clients/patients or providers to identify practitioners who deliver these treatments (Patel, Butler, & Wells, 2006). Quality of care is hampered further when service systems and practitioners are not up-to-date with current science (Braun, n.d.).

In this section, I have discussed risk factors for MI in rural, frontier, and territory communities. These are risk factors in general and not necessarily generalized to all rural residents. Rural areas are not homogeneous. Other characteristics, such as those previously mentioned, and age, level of adherence to traditional or indigenous practices, regionally specific characteristics, and other cultural and regional attributes are intervening and moderating factors for risk.

Dual Diagnosis

Comorbidities are related to multiple issues including substance use and psychiatric disorders, multiple psychiatric disorders, and psychiatric or substance abuse disorders and a health-related diagnosis (Gray, 2011). (See Chap. 28 for discussion on substance abuse.) A large number of people with MI have comorbid substance use or physical health conditions (Greenberg, 2012). People with SMI have a higher prevalence of diabetes and heart disease (Miller, Paschall, & Svendsen, 2006), and many medications used to treat SMI also increase risk of diabetes (American Diabetes Association et al., 2004). Some people who are SMI take drugs or alcohol to alleviate their symptoms (self-medicating). Frequently, these individuals are undiagnosed as having a mental disorder. Other individuals with a diagnosis may stop taking their medications in order to use a substitute substance. Yet, others who are chronic substance abusers may trigger a mental disorder, known as a drug-induced disorder. Whatever the circumstance, individuals who are dually diagnosed rarely receive simultaneous treatment for their mental disorder and their substance abuse (Russell, 2010).

Patients or clients with dual diagnoses have therapeutic challenges presented by comorbid psychiatric and substance abuse disorders. The effect of excessive substance use on an individual's mental well-being can present as a diagnostic challenge as each condition may mask symptoms of the other (Deans & Soar, 2005). Often, dual-diagnosed clients are difficult to work with because as a group they tend to seek services for substance abuse treatment only as a result of personal, family, or legal problems. In addition, they frequently have fragile support systems because behaviors associated with their diagnoses have depleted these systems. Another reason dual-diagnosed clients present a challenge in treatment is because they have "interchangeable denial" that involves the utilization of one problem to defend the other (Doweiko, 2015, p. 353). For example, a client with bipolar disorder will want to talk about his or her substance use disorder when the mental health professional is focused on the MI. On the other side, if the rehabilitation professional wants to focus on the substance use disorder, the client will want to talk about his or her bipolar.

The difficulty in working with dually diagnosed client is not necessarily the fault of the client. There is a "professional blindness" in which healthcare professionals view dual-diagnosed clients as being primarily substance-abusing patients who require addiction treatment (Doweiko, 2015, p. 354). Conversely, the rehabilitation professional views the same client as being a psychiatric patient. The result is that the client goes back-and-forth between the two programs (Doweiko). According to the Parliament of Australia (2006), the erosion of the skill base among psychiatrists and nurses is in part a consequence of the specialization of service delivery into separate and distinct silos, for example, MH against substance disorder services. In addition, clinicians in rural areas working with dual-diagnosed patients experience frustration, resentment, and powerlessness in their attempt to understand their clients' drug misuse and simultaneously trying to provide MH services (Deans & Soar, 2005). In rural areas, the client potentially will not receive treatment for neither of his or her diagnoses because of barriers previously discussed.

Social and Economic Costs of Mental Illness and Dual Diagnoses

The economic costs of MI have never been easy to pinpoint but can be estimated much the way we estimate other healthcare costs (Insel, 2008). However, much of the economic burden of MI is not the cost of care but loss of income due to unemployment, expenses for social supports, and a range of indirect cost due to a chronic disability that begins early in life (National Institute of Health, 2011). Mental illness and/or substance abuse have direct and indirect costs. The direct costs refer to treatment expenses and include increased medical expenditure and costs for long-term care. Poor mental health drives up the costs of treating other health conditions (Insel, 2008; Wu et al., 2005). More than half of all mental health expenditures are paid for by the public sector (Medicaid, Medicare, state, and local government) and individuals with MI or SMI account for approximately 32% of recipients that qualified for Supplemental Security Disability Insurance (SSDI) as of 2013 (National Alliance on Mental Health, n.d.). Likewise, in England, mental illness represents the single largest cause of disability and the most costly for the government in terms of treatment, welfare benefits, and lost productivity at work (McCrone et al., 2008). Indirect costs refer to non-health costs. From a broader social perspective, people with SMI or untreated MI and/or dual diagnoses experience higher rates of unemployment, are poorer than the general population, and have more absences from work, reduced productivity at work, high worker compensation claims, low levels of job satisfaction, high rates of occupational injury, and higher rates of domestic violence. These factors lead to significant indirect economic costs (Insel; OECD, 2014).

People with SMI have a life expectancy on average of 25 years less than people without SMI (National Association of State Mental Health Program Directors, NASMHPD, 2006). An overwhelming majority of people who committed suicide had a SMI (Ruter & Davis, 2008), and those with dual diagnoses have greater risk of suicide attempts than non-dual diagnoses (Gimelfarb & Natan, 2009). People with dual diagnoses experience the worst social and health outcomes including homelessness, forensic involvement (criminal justice system), and more exposure to violence and exploitation both as victim and perpetrator (Honberg et al., 2011; Parliament of Australia, 2006). In general, people with dual diagnoses have a higher level of need than other cohorts with mental illness and a poorer prognosis compared to those with either a mental or substance abuse disorder alone (Parliament of Australia).

The social interference of mental illness and dual diagnoses will vary from person to person depending on severity, treatment compliance, and supports. In general, MI can interfere with a person's ability to think clearly, manage emotions, make decisions, and relate to others. People can experience multiple symptoms, both emotional and physical. While these symptoms and experiences are not unique to people in RFT areas, availability and access to resources to which to respond can alter the outcomes for rural residents.

Rethinking Approaches to Service Delivery in Rural Areas

Russell (2010) described the US mental health service delivery system as "pluralistic and minimally coordinated, with a persistent division between public and private sector providers, …" which "makes it difficult to translate methods for estimating workforce adequacy from health to mental health" (p. 31). If disability due to mental disorders and dual diagnoses in rural areas is to be reduced, the treatment gap in mental healthcare must be reduced. "The treatment gap refers to the absolute difference between the true prevalence of a disorder and the treated proportion of individuals affected by the disorder" (Kohn et al., 2004, p. 859). Thus, the solution to addressing the healthcare needs of persons with SMI and substance use disorders and behavioral health needs is straightforward: (a) close the gap between those who require treatment and do not receive it; (b) better integrate medical and behavioral healthcare, as well as substance use and mental healthcare; and (c) expand the use of evidence-based practices to coordinate care, treat behavioral health disorders, and treat chronic mental conditions (National Council for Behavioral Health, 2015). According Gale and Lambert (2006), there is a renewed interest in the integration of MH and primary care services, particularly in rural areas. This large interest among rural primary care providers in learning about MH issues follows the national trend for greater integration of primary and MH care and suggests that they are aware of the impact of MH on their patients' physical health (McFaul et al., 2009).

Integrated Health and Mental Health Services Behavioral health services are divided into three focus areas: mental health, substance abuse, and domestic violence (Eilrich, St. Clair, & Doekse, 2005). Eilrich et al. assert that these divisions create barriers to care because frequently the proper treatment involves more than one of these areas. In addition, comorbidity disorders are recognized beyond only behavioral health because individuals with serious or chronic physical health problems often have comorbid behavioral problems (Kessler, Chiu, Demler, & Walters, 2005). For many people, their mental disorder is a chronic condition; thus, mental illness needs to be included alongside other chronic conditions when protocols and strategies are established to better address and manage them. Addressing mental illness as comorbidity with other chronic conditions is an important way to treat patients, improve quality of life, and reduce healthcare costs (National Council for Behavioral Health, nd; Russell, 2010). Likewise, the National Rural Health Association (2013) asserts that integrating primary care and behavioral health increases access to behavioral healthcare for rural residents, and when the two services are provided in the same healthcare setting, people are more likely to take advantage of the behavioral health services. Accessing mental health services through rural primary care provides a type of privacy for the client/patient. When an individual is seen entering the physician's office, there is no incidental reveal that he or she is accessing MH services. In addition, stigma is reduced for the client as well.

Unuter and Druss (2013) discuss the collaborative care model, which represents an evidence-based approach to physical-behavioral health integration. The model is an example of strategies to improve the integration of behavioral and physical healthcare and an innovative payment model to cover the costs of care. The model is implemented within a primary care-based Medicaid health home model and among other settings. Collaborative care includes (a) care coordination that can be care management, (b) regular/proactive monitoring and treatment to target using validated clinical rating scales, and (c) regular, systematic psychiatric caseload reviews and consultation for patients who do not show clinical improvement (Unuter & Druss). Ouimette et al. (2007) stressed that understanding how to implement evidence-based practices is critical to improving care of dual diagnosis patients because when best practices are not consistently implemented and when administrative barriers exist, provision of more effective care is hindered.

Efforts to integrate service delivery should be approached in two ways: (a) short-term strategies and (b) long-term methods. In the short term, service providers need to identify strategies to provide immediate response to RFT residents who are experiencing MI while simultaneously expanding outreach and prevention services. Long-term methods first must change the culture of medicine and affiliated healthcare professions, the ways these services are delivered, and funding and reimbursement guidelines. Both short-term and long-term approaches will require those who deliver MH services and medical care to initiate and sustain change (Russell, 2010). Yet, after the passage of the Mental Health Parity and Addiction Equity Act of 2008, there is little evidence that the system of mental healthcare has been transformed or that the burden of MI has been reduced (Greenberg, 2012).

Public Education Collaborative Moore et al. (2005) recommended the establishment of a public education collaborative that can inform rural residents of the importance of early intervention for MI. As author of this chapter, I offer the following recommendations for consideration. One of the major barriers to informing rural residents about MH screening and early intervention is the inability to disseminate information in an effective and efficient way across sparsely populated regions. In part, this is due to the digital divide between rural and urban areas. One solution is that libraries can facilitate online access to health information among vulnerable and underserved populations (Kreps, 2005). Another possibility is to use Cooperative Extension offices. Each county in states with an agricultural base has an extension office. A third strategy is to have medical and dental outreach programs distribute information on MH well-being as part of their outreach program. Not only is this a way to disseminate information, but doing so as part of healthcare services is a way to not call attention to MH information as something separate from healthcare, thus reducing the stigma.

Telemental Health Telemental health counseling (also known as telebehavioral health or telepsychiatry) is another approach that has been implemented in rural areas. Telemental health employs the use of telecommunication technology to deliver behavioral or mental health services. Delivery of services is typically divided into two categories: synchronous and asynchronous. Synchronous is live, real-time interactive two-way communication (i.e., telephone, video teleconferencing). Asynchronous is not in real time and usually involves the transmission of reports or information to a distant site to review at a later time. Telemental health offers the advantages of increasing availability of services to clients in RFT areas, decreasing costs, and saving or maximizing time and effort. Because mental healthcare often requires a multidisciplinary team approach to best serve the client, telemental health allows for provider-to-provider consultation. Furthermore, this approach can be incorporated easily into the method of integrating primary care and MH care. It is generally agreed that health information technologies can help providers manage the complex chronic care needs of rural residents that have scarce access to medical specialties. However, connectivity issues in most rural areas remain a problem. Connectivity refers not only to the availability of the Internet and broadband services but also disruptions in service, for example, because of hunters shooting down power lines (Hook, Grant, & Samarth, 2010).

Telemental health has long been promoted in RFT areas in response to chronic access barriers to HM care and continues to be supported. To better understand the current status that telemental health plays in today's rural healthcare system, Lambert, Gale, Hansen, Croll, and Hartley (2013) conducted a national study of rural healthcare programs. The key findings were:

1. The scope and volume of services provided are often modest, suggesting that the business case for these programs may be weaker than the clinical.
2. Programs were able to secure funding and other supports to implement services, but their ability to maintain and expand services to meet needs is less certain.
3. Telemental health primarily addresses issues related to the distribution of providers and travel distances to care. However, there are underlying practice management issues, common to all MH practices in rural areas, which pose challenges to sustainability.
4. It is becoming increasingly apparent that telemental health technology, by itself, cannot overcome service delivery challenges

> without underlying reform to the MH service system (p. 1).

Although telemental health is being increasingly used in RFT areas, the results of this study raises question about the views of advocates of the approach of telemental health in rural areas. Lambert et al. found that some advocates viewed telemental health as a panacea without understanding the underlying financial and organizational challenges of delivering MH services in rural communities. The quality and continuity of MH care through the use of telemental health in RFT areas also might be compromised. See Research Box 26.2. (See Chap. 26 for additional information on the use of technology.)

Peer Support Counselors A growing practice in mental health services is the utilization of peer support counselors. According to Jain (2013), hiring peer support counselors represents innovation in the delivery of rural mental healthcare. Peer support consists of a peer support provider, who has a lived experience with mental illness, and, having experienced significant improvements in their own condition, offers services to a peer considered to be not as far along in their own recovery process. The premise is that the life experiences of peer support counselors allow them to provide recovery support in such way that others can benefit from their experiences. "A peer support counselor can leverages shared experiences to foster trust, decrease stigma and create a sustainable forum for seeking help and sharing information about support resources and positive coping strategies," … "promote awareness among the target populations, and speak the same language as those they are helping as a result of shared experiences" (Money et al., 2011, pp. 4–5). In a formalized peer-to-peer program, the peer providing the support has received some level of training and has access to more intensive support resources (Money et al., 2011). A peer support counselor can become certified (i.e., Nationally Certified Peer Recovery Support Specialist [NCPRSS]) (National Association for Addiction and Drug Abuse Counselors [NAADAC], 2013).

Research Box 26.2: See Lambert (2013)

Objective: To better understand the role that telemental health plays in today's rural healthcare system.

Method: A national study of rural telemental healthcare programs was conducted in two phases. In the first phase, a list of telemental health programs was compiled by (a) reviewing grantee directors for relevant program (i.e., Office of Rural Health Policy (ORHP), Health Resources and Services Administration), (b) soliciting nominations from a national advisory group of rural telemental health experts recruited for this study and ORHP-funded Telehealth Resource Centers, and (c) conducting extensive web searches. This process generated 150 programs that were invited to complete an online survey. Data were collected on organizational context, services provided, staffing patterns, and the areas and populations served. In phase two, semi-structured telephone interviews with administrators from 23 programs were conducted to understand the business and clinical environments in which these programs operate, their successes and challenges in establishing programs and delivering services, and the prospects for and challenges of long-term sustainability.

Results: Sixty programs responded (40% response rate), of which 53 provided a use profile of what current rural telemental health programs are doing. Based on the responses, academic medical centers are the most common settings for telemental health programs. Other common settings included community mental health centers, acute care hospitals, private vendors, Federally Qualified Health Centers, and Rural Health Clinics. Organizational uses of telemental health technology were direct patient care, consultation between providers, care management/coordination, staff supervision, and quality improvement activities. Direct services provided included medication management, initial diagnostic evaluation, psychotherapy, crisis stabilization, involuntary commitment assessment, substance abuse treatment, and crisis management. Mental health professionals providing telemental health services were psychiatrists, clinical psychologists, clinical social workers, and psychiatric nurse practitioners (these were not mutually exclusive). Rural telemental health programs are located across a range of organizational settings: free-standing/independent facilities, networks, and large health systems. The current and future role of telemental health in the rural health system included access, reimbursement, patient and provider satisfaction, and successful use of telemental health.

Conclusion: It is important not to overpromise what telemental health can accomplish. Equally important is to recognize that telemental health can play an important role under the payment and service delivery models established or promoted under the Affordable Care Act. Telehealth may have a role to play in achieving a balance between access to care, cost containment, and meeting the needs of the population.

Questions

1. What other type of sampling methodology would you use to conduct this study?
2. What are the implications of these results for rural geographically diverse regions (e.g., Alaska, Montana, Maine, Texas)?
3. What are the limitations of this study?

Money et al. (2011) describe four models that demonstrate how peer-to-peer programs can be structured: *support group*, *peer mentor*, *community health worker*, and *peer educator*. A *support group* includes multiple individuals meeting to share experiences. The advantage of a support group is that it provides an opportunity to learn from others' experiences and more opportunities to strengthen the social network. The disadvantage is that a support group can be difficult to start, and it requires administrative support and multiple participants. A *peer mentor* is an individual that meets with an individual on a one-to-one basis. The strength of a peer mentor model is it involves individual attention and advocacy. The limitation of this model is that it is dependent on the abilities of the peer mentor. A *community health worker* serves as a liaison between a target population and MH and healthcare providers and may not always be a "true peer." The major strength of a community health worker model is the ability to build a bridge between service providers and individuals not already in care. The chance that peers may be absorbed into a healthcare provider system and lose their peer status is a limitation of this model. The *peer educator* model is where a peer provides an educational course with discussion time. This model provides access to information as well as recognition that there are others in the same situation. On the down side, the peer educator model is a short-term intervention and does not provide ongoing support. An overall advantage of any of the models is that peer support can be delivered through multiple modalities, including in person, by phone, or over the Internet. These models can be used individually or in combination with each other, offering more than one option to clients (Money et al., 2011).

There are numerous benefits to a peer support counselor. One benefit is that peer support counselors have a perceived sense of credibility. That is, they have personal experience as a frame of reference. Another benefit is that they interact more frequently with the person in counseling than do MH professionals or others of the medical community. As a result, peers are most likely to notice changes in behavior and personality of an individual (Money et al., 2011) (see Table 26.3). In fact, Money et al. describe the roles and func-

Table 26.3 Benefits of peer support counselor

Creates an environment of credibility
Reduces stigma by providing a platform for discussion
Increases the number of social relationships for the peer
Provides education to support positive coping behaviors
Promotes cohesion between service providers and clients
Serves as a liaison between the client and behavioral health professional
Increases outreach to individuals who might not be currently using MH services
Provides information on resources available beyond the immediate peer supporter
Facilitates referrals of individuals needing professional assistance before or when a crisis event occurs
Provides benefits to the individual participant, peer supporter MH and healthcare providers, and surrounding community

Adapted from Money et al. (2011)

tions performed by a peer supporter as interconnected benefits.

Professional Licensure and Professional Credentials Professional licensure of mental health counselors, clinical social workers, and professional counselors is regulated at the state level. In other words, each state sets its own standards and qualifications. A barrier often imposed on professionals that deliver MH services is that they can only practice in the state in which they are licensed. For clients that live along a state or territory border, it may be closer for them to receive services from a neighboring state; however, to do so is prohibited by licensure laws. Gray (2011) recommends allowing licensing for multiple states in a region as a means of addressing the needs of providers along state and territorial borders. In addition, there is also variation among occupations depending on level of specialized training, certifications, and specific industries. Reimbursement to rural health clinics requires additional education and certification requirements (Eilrich et al. (2010). For example, psychologists must be doctoral level, and clinical social workers and psychiatric nurse practitioners must be master's level.

Perhaps the era of specialized training has come full circle, and there is a need for cross sector training and skills development and licensure or certification so the MH professionals and drug and alcohol counselors can effectively support individuals with dual diagnoses of both MI and substance abuse disorder, regardless of which service they are initially referred (Parliament of Australia, 2006).

Recovery and Employment

In 2000, NAMI issued a call to state agencies to increase among their ranks the number of employees with MI. The intent was to move the mental health system toward a recovery-based model. Unemployment of individual with MI is consistently and persistently high. Among clients served by public mental health systems, unemployment is more than three times that of the general population (Lutterman, 2012, 2013). Education, which is considered as a shield against poverty, has not been an effective hedge against unemployment or underemployment for those with MI (Cook, 2006). For many clients with dual diagnoses in RFT, communities reentering or maintaining employment presents an ongoing challenge (NAMI, 2012).

Often, individuals with MI may need support in the workplace. Supported employment, which is paid, competitive employment in an integrated setting with ongoing supports, is an evidence-based practice that is effective for persons with disabilities. Promising models for employment include Individual Placement and Support (IPS) Supported Employment, Assertive Community Act and Supported Employment, clubhouses, internship to employment, self-employment, and volunteering (NAMI, 2012). IPS is designed to help individuals with MI find jobs in the competitive marketplace, and it (a) tailors employment services to match the person's needs, talents, and preferences; (b) prioritizes rapid job search and placement, as well as long-term availability as long as support is needed; and (c) calls for employment services to be integrated into the individual's MH treatment plan with an employment specialist working as a member of the treatment team (NAMI, 2012). ACT is another evidence-based program that uses a multidisciplinary team approach and offers comprehensive MH services when and wherever needed (SAMSHA, 2008). In addition to support employment, ACT provides an array of services including mobile crisis intervention to individualized support therapy to supported housing and transportation. ACT teams have small caseloads with services available 24 h a day, 7 days a week, in locations such as home, work, or community (NAMI, 2012).

Clubhouses are community-based centers that use an egalitarian, inclusive approach where club members and staff work together to operate the program. Clubhouses offer a wide range of services. Those centers that are certified by Clubhouse International offer employment services. Internships offer people with MI to gain work experience with their career goals and are usually part of an educational program. "Internships offer a low-risk opportunity to explore the fit between individual aspirations and workplace expectations" (NAMI, 2012, p. 10). An alternative to traditional work settings for people with MI is self-employment and small business ownership. These options provide flexible work hours and workplace location. In addition, they allow individuals to capitalize on their unique creativity, promote innovation, and offer the opportunity to pursue specialized talents (NAMI, 2012). Finally, a practical route to employment is through volunteering. Volunteering offers individuals with MI the chance to transition into the workforce by taking on responsibility, learning new skills, interacting with others, and receiving recognition and feedback. Volunteering provides a test run in which neither the individual nor the employer is lock into performance criteria.

These evidence-based approaches to gainful employment provide the individual with opportunity to practice the job and learn skills and employers an opportunity to assess the individual's skills and workplace behavior. In addition, for those who receive disability benefits, supported employment provides a chance for employment and a security net of not losing benefits. In rural areas where job opportunities are less available, these approaches can provide support to the employer and individual for implementing workplace accommodations. In the end, supported employment for individuals with MI improves.

Summary

Mental illness affects people from all walks of life; however, the extent of its impact is disproportionate in rural areas due to numerous barriers. Rural, frontier, and territory communities are diverse, with different levels of services. RFT areas are disproportionately and adversely impacted by MI and dual diagnosis because of a combination of risk factors and low service accessibility. The outcome is reflected in a potential for loss of life and loss of jobs, productivity, and income. The gaps in treatment, funding, and personnel shortages must be addressed in RFT areas. Recognizing the complexity involved identifying and implementing strategies in mental health, and substance abuse treatment in RFT areas requires that policy and funding becomes a priority. If the argument against increased funding to MH clinics and services is that it is costly, one can only imagine the cost of not providing care.

Resources

Assertive Community Treatment (ACT) Evidence-Based Practices (EBP) KIT: http://store.samhsa.gov/product/Assertive-Community-Treatment-ACT-Evidence-Based-Practices-EBP-KIT/SMA08-4345

Behavioral Health Barometer – US 2014 (SAMHSA): http://www.store.samhsa.gov/product/Behavioral-Health-Barometer-2014/SMA15-4895

Dual Diagnosis Capacity in Mental Health Treatment (DDCMHR) Toolkit – Version 4.0: http://dartmouthprc.org/wp-content/uploads/DDCMHT_Toolkit.pdf

National Alliance on Mental Illness: http://www.nami.org

National Association for Rural Mental Health: http://www.narmh.org

National Institute of Mental Health: http://www.nimh.nih.gov

Substance Abuse Mental Health Services Administration: http://www.samhsa.gov

Learning Exercises

Self-Check Questions

1. Why is there a renewed interest in integration of mental health services with primary health services in rural areas?
2. Explain what is meant by mental health and mental illness exists on a continuum.
3. How are dual diagnoses defined?

Experiential Exercises

1. Identify a specific mental illness and a coexisting mental health condition or addiction and develop an approach to address this dual diagnosis for an individual residing in a rural, frontier, or territory community.
2. Construct a framework on policy to address mental health service delivery in rural areas.
3. Identify a current mental health concern in a rural area and discuss how it is impacted by economic circumstances, cultural considerations, and regional or geographic situations.

Multiple-Choice Questions

1. Which of the following are the most commonly diagnosed mental health disorders?
   (a) Depression and anxiety
   (b) Anxiety and bipolar
   (c) Manic disorder and substance abuse
   (d) Schizophrenia and mood disorders
2. Which of the following is a primary reason that treatment for mental illness has shifted to the primary healthcare sector in rural areas?
   (a) High costs
   (b) Personnel shortage
   (c) County regulations
   (d) Community expectations
3. Fear of seeking mental health treatment in rural areas is closely associated with which of the following?
   (a) Culture
   (b) Stigma
   (c) Shame
   (d) All of the above
   (e) None of the above
4. Which of the following is the most common reason as to why many rural residents are often reluctant to seek mental health or substance abuse treatment?
   (a) Costs
   (b) Lack of transportation
   (c) Religious reasons
   (d) Privacy
5. Which of the following can be both an asset and barrier to rural residents seeking treatment for mental illness or substance abuse disorders?
   (a) Weather and climate
   (b) Family size
   (c) Protective factors
   (d) Age
6. Which of the following is true of a peer support counselor?
   (a) Perceived not to have credibility
   (b) Less likely to notice changes in a peer's behavior and personality
   (c) Have personal experience as a frame of reference
   (d) Likely to less frequent contact with the peer than do mental health professionals
7. Which of the following statements most accurately describe the difficulty in working with dually diagnosed clients?
   (a) Clients are too unstable
   (b) Professional blindness

   (c) Time management problems
   (d) Direct cost of services
8. Which of the following exacerbates the shortage of qualified personnel for individual with mental illness or substance abuse disorders that live in rural areas along state lines in which the closest service provider is in another state?
   (a) The professional can only practice in the state in which he or she is licensed
   (b) The professional usually charge higher for out of state clients
   (c) The professional is likely to have less contact with the client
   (d) The professional is less likely to provide an educational course with discussion time
9. Which of the following best describe the collaborative care model?
   (a) Care coordination can be care management
   (b) Use regular monitoring and treatment with validated clinical rating scales
   (c) Use regular and systematic psychiatric caseload reviews and consultation
   (d) All of the above
   (e) None of the above
10. If disability due to mental illness and dual diagnoses is to be reduced in rural areas, which of the following needs to be addressed?
   (a) The availability of supported employment
   (b) The treatment gap
   (c) The competency of counselors
   (d) The success of consultation

Key

1. A
2. B
3. D
4. C
5. C
6. C
7. B
8. A
9. D
10. B

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Multiple Sclerosis Among Rural Residents: Treatment, Psychosocial Implications, and Vocational Implications

Michael Frain, Bradley W. McDaniels, and Malachy L. Bishop

Overview

Multiple sclerosis (MS) is chronic, neurologic condition that generally affects individuals in their most fruitful working years (20–30 years old). Although the medical community is continually advancing novel treatments for MS, there is no cure, and one is not expected in the near future. The challenge for those with MS is to find effective interventions to ameliorate the symptoms associated with MS, which may allow them to remain functional and retain a good quality of life. Most individuals with MS have employment histories, but many choose to leave the workforce as a result of their symptoms (e.g., depression, fatigue, mobility), but literature indicates that the majority would like to return to work if possible.

Because of the lack of available resources in rural communities, those with MS are frequently underserved. Rural communities often lack specialty care (e.g., neurologists, physical therapists, occupational therapists, counselors), which are all necessary for the overall well-being of people with MS. Rehabilitation counselors (RCs), who view individuals holistically, are uniquely positioned to offer services that can improve both employment and quality of life for those with MS. RCs can serve as a point of contact and a source of information that can assist individuals in learning about MS and identifying problematic symptoms. An important consideration for RCs is that without addressing the accompaniments of MS, employment will remain precarious.

Learning Objectives

By the end of the chapter, the reader should be able to:

1. Understand the nature and course of MS and its symptomatology
2. Explain the challenges faced by individuals with MS living in rural areas
3. Have an understanding of the MS self-management scale and its importance to individuals with MS

Introduction

Multiple sclerosis (MS) is a chronic, progressive, autoimmune demyelinating disease of the central nervous system affecting approximately

M. Frain (✉)
Florida Atlantic University, Department of Counselor Education, Boca Raton, FL, USA
e-mail: mfrain@fau.edu

B.W. McDaniels
University of Kentucky, EDSRC Department, Lexington, KY, USA
e-mail: bradely.mcdaniels@uky.edu

M.L. Bishop
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: mbishop@uky.edu

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1 in 750 people in the United States or about 400,000 American at any one time (Fraser, Kraft, Ehde, & Johnson, 2006; National Multiple Sclerosis Society [NMSS], 2015). MS affects about 2.3 million people worldwide; some nationalities seem greater affected than others (Browne et al., 2014). The typical course of MS is characterized by alternating episodes of neurological symptoms and remissions, with symptomatic phases including fatigue, mobility limitations, cognitive impairments, affective disorders, visual impairments, bowel and bladder dysfunction, and sexual dysfunction. MS symptoms frequently intensify over time, leaving the person with increased physical disability and declining general health (Buchanan, Wang, Martin, & Ju, 2006). Although the physical effects of MS are typically considered the primary source of disability, the consequences of the disease on affective well-being are equally important and frequently overlooked (Moore et al., 2012). MS is one of the most commonly diagnosed neurological conditions in North America and the leading nontraumatic cause of nervous system disabilities in young adults (Myhr, 2008).

MS is a disease that typically strikes younger individuals, usually in their late 20s or early 30s, when the first signs of the disease become evident. Following the initial onset of symptoms, functional and physical decline will progress over the next 30–40 years of life (Pugliatti et al., 2006). As a result of the previously mentioned sequela of MS and the challenges associated with effective and efficient care, those with MS require more services while also reporting greater unmet health-care needs when compared to other disabilities (Pohar, Jones, Warren, Turpin, & Warren, 2007). Because of the multitude of functional implications associated with MS, family members, friends, and paid caregivers are often needed to assist individuals with activities of daily living (Gottberg et al., 2008). In addition to the assistance frequently required to complete daily activities, people with MS report additional barriers regarding the availability of services in their community. Transportation services are commonly noted to be of importance for many people with MS due to inconsistent or lack of driving ability. Moreover, literature indicates that individuals living in rural areas have limited access to health-care and specialty services making transportation difficult due to long travel distances to access proper care. For those with MS living in rural communities, the issue of transportation is compounded. The unavailability of public transit, paratransit, and other modes of transportation results in greater challenges (see Chap. 3). Another identified concern is the availability and accessibility of home health services. Due to the increased functional limitations associated with the progressive nature of MS and the transportation barriers, inadequate home health services may not only affect proper care but may also result in people with MS losing their independence associated with living at home and may lead to one having to move into a long-term care facility (e.g., Galushko et al., 2014).

Although most people with MS express the above needs, it is clear that equitable services are not routinely available to all. Rural residents with MS are more likely to have unmet service needs resulting in additional challenges to receiving comprehensive care. The necessity of having access to a neurologist has been identified as a primary concern for individuals with MS. Unfortunately those with chronic conditions living in rural communities typically live in areas that are already drastically underserved (Wilper et al., 2008). Therefore, providing individuals with MS the essential high-quality primary and specialty care (e.g., physical therapy, occupational therapy, neurology) continues to be confounding. MS centers, arguably the most advanced care, are commonly located in larger, metropolitan cities where major universities reside, which preclude many in rural communities from receiving the most up-to-date treatments.

Psychosocial Aspects

Literature suggests that many (55%) with MS require assistance walking, 50% need assistance from others to perform personal care activities, and roughly 60% require assistance with activities of daily living (Bishop, Rumrill, & Timblin, 2016;

Bishop et al., 2013; Davis & Tyry, 2008). The course of MS varies from person to person, and the symptoms are wide-ranging, affecting nearly every aspect of one's life (e.g., employment, social interactions, leisure activities; Antao et al., 2013). In addition to the physiological symptoms of MS, cognitive and affective associations are also significantly identified. Research suggests that 60–65% of individuals with MS have challenges with attention, conceptual reasoning, executive functioning, social judgment, and memory (Polman, Thompson, Murray, Bowling, & Noseworthy, 2006). Among the potential affective complications associated with individuals with MS, depression is the most common and potentially the most debilitating accompaniments with 50% experiencing at least one major depressive episode throughout the course of the disease (McReynolds & Koch, 2001). Adjusting to the constantly changing presentation of MS is one of the overriding challenges for individuals and their families.

Caregivers

Because of the unpredictability of MS, caregivers are faced with not knowing when additional help may be necessary or how to effectively administer such assistance. Caregivers carry a significant amount of responsibility for their loved ones with MS but receive limited help from health-care professionals (Labiano-Fontcuberta, Mitchell, Moreno-García, & Benito-León, 2014). Therefore, not only is addressing the needs of the person with MS important, but also providing appropriate interventions to ensure that caregivers remain well and able to provide the necessary assistance is a key to maintaining health and family involvement. Family and caregivers are intimately involved in helping their loved ones cope with the physical and psychosocial effects of the disease and can frequently result in caregiver "burnout." One of the reported benefits of living in rural communities is that rural individuals are more likely to have a social network that will help with these needs if asked versus urban dwellers (Golla, Malhotra, Nanda, & Mehra, 2011). Rural communities have a tradition of helping neighbors in need but often feel unqualified to help. Rehabilitation professionals can assist by disseminating information to communities. Getting information about MS to caregivers or community friends may be best achieved through the Internet, community media, and other local resources (e.g., Buchanan, Huang, & Crudden, 2012); however, the level of availability of the Internet is a concern (see Chap. 4). Given the complex physical, psychological, and social impact of MS on the lives of both patients and caregivers, identifying what patients and caregivers perceive to be unmet needs, particularly in rural communities, is warranted.

In the United States, more than one in five adults provides unpaid care to another adult age 18 or older. In rural areas, the majority of caregivers are married, women, and white, have low income, have children or grandchildren, live within a 1-h drive of the care recipient, have provided care for 10 years or more, and spend an average of 21 h per week caregiving (Easter Seals Disability Services & National Alliance for Caregiving [ESDANAC], 2006). Caregivers report the following unmet needs: (a) finding time for oneself, (b) managing emotional and physical stress, and (c) balancing work and family responsibilities. In addition, caregivers report needing help in keeping the care recipient safe, finding easy activities to do with them, talking with doctors and other health-care professionals, or making end-of-life decisions. To provide care, rural caregivers have had to make workplace accommodations including taking time off and/or leave their job early, taking a leave of absence, dropping from full-time to part-time employment, turning down a promotion, taking early retirement, losing some job benefits, and giving up work entirely (ESDANAC). The impact on rural caregivers and care recipients is usually a reduced standard of living and increased stress.

Social Involvement

The unpredictable and progressive nature of MS can have a significant effect on an individual's social involvement. We have discussed a number of functional changes associated with MS (e.g., mobility, bowel and bladder control) that can present significant challenges for individuals with MS to maintain their previous level of participation in social and community activities (e.g., sports, religious). Fatigue is commonly reported by individuals with MS, and two-thirds of people report that it negatively affects their ability to fulfill social and employment responsibilities (Berger, Pocoski, Preblick, & Boklage, 2013) As a result of the decrease in social involvement, many individuals with MS may suffer social isolation. Additionally, stigma and discrimination may contribute to one's decision to restrict activities outside the home (Halper, 2007). In rural areas, mobility issues are often a community issue as much as an individual one. Mobility is a common impairment for people with MS, and it has been estimated that within 10–15 years of an initial diagnosis of MS, approximately 80% of patients will experience some degree of impaired mobility (Souza et al., 2010).

Because friends and services essential for daily life are further away in rural communities, without appropriate interventions, the lack of mobility can lead to isolation. Rehabilitation professionals need to be aware of the importance of social interaction on the well-being of individuals with MS and be prepared to provide optimal support.

Employment

Not only does MS affect one's family, caregivers, and social involvement, there is a deleterious impact on employment. Most individuals with MS experience the onset of symptoms in the height of their employment careers, but only a minority of individuals maintain employment following their initial diagnosis (Roessler, Neath, McMahon, & Rumrill, 2007). Of the individuals with MS who are unemployed, 75% claim they would like to return to work (Rumrill, 2006). Research indicates that employment is correlated with "well-being and quality of life, and provides access to economic security, increased opportunities for social participation, and access to health insurance and health care" (Chiu, Chan, Bishop, da Silva Cordoso, & O'Neill, 2013, p. 1656). Living in a rural community creates additional barriers to employment such as (a) fewer employment options, (b) employer discrimination, and (c) inadequate transportation. Frequently, individuals living in rural areas commute to metropolitan communities to find suitable employment, which is a challenge for individuals with MS. The profession of vocational rehabilitation counselor emphasizes "individual" plans for employment and education with the individual being the director of all plans. The field understands that without person-centered employment planning and the support of significant others, the plan will likely fail.

Medical

With pioneering spirits and independence continuing to thrive in rural areas, health-care providers would be wise to understand rural culture, belief systems, values, and contextual factors into health-care programs and services. Health-care professionals should adopt the approach that rural individuals will choose whether to accept health care and not blindly comply with health-care directives. Understanding the importance of the self-management of one's MS, Bishop and Frain (2007) developed the Multiple Sclerosis Self-Management scale (MSSM) , which provides a method of assessing self-management knowledge and behavior among adults with MS. Rural individuals with MS can use the tenants of the MSSM, self-management, perception of control, and awareness, by understanding how adherence levels affect personally important aspects of life (e.g., ability to work, ability to fulfill life roles). Taking medication in order to extend one's life may matter less to a rural farmer than taking medication that allows them to be healthy enough to complete their duties on the farm.

Health-care services are more effective when tailored to fit within the schedules of those living and working in rural communities because many rural inhabitants frequently avoid health care until necessary functions have been fulfilled (Weihart & Long, 1987). Ranchers, farmers, and other occupations, which are more typical in rural environments than urban settings, often come with no paid days off and no health insurance. The ability to take care of health concerns during planting season is not realistic, just as taking time off on April 14 is not an option for a tax accountant. Health-care professionals who are outsiders and come into rural settings and attempt to impose their will on the community will often find a community chooses to seek other health-care options. It may take 5–10 years to be accepted as a regular part of the community for health-care professionals much different than the ever-changing caseload often seen in an urban setting. Health-care providers have an opportunity to provide instruction and relief for individuals and family members and frequently may be the sole professional providing care for individuals with disabilities and/or chronic illnesses. Trust and confidence are especially essential in rural communities, and because there is limited emigration, rural inhabitants develop strong relationships and are cautious of those from metropolitan areas. This creates challenges for rehabilitation counselors who cover broad geographic areas that include rural communities because they, too, are viewed with skepticism.

Self-Management

Self-management has become recognized as a beneficial strategy for improving physical and psychological well-being and quality of life for individuals with chronic health conditions (Bycroft & Tracey, 2006; Lorig & Holman, 2003). Self-management may be loosely defined acquiring and implementing the skills needed to carry on a physically and emotionally satisfying life despite chronic conditions (Lorig, 1993). MSSM attempts to discover a number of dimensions of particular importance to individuals with MS and includes (a) treatment adherence and barriers, (b) knowledge and understanding of MS, (c) daily management of one's MS, (d) actively participating in health-care decision-making, and (e) managing the impact of MS on physical, emotional, and social life (Bishop & Frain, 2011). Research clearly elucidates the benefits of self-management and its associations with positive health and rehabilitation outcomes including (a) increased perceived control over both illness and nonillness aspects of one's life (Bishop, Frain, & Tschopp, 2008; Devins & Shnek, 2000); (b) reduced hospitalizations and medication expenses (Lorig, Ritter, Laurent, & Plant, 2006); (c) improved quality of life (Cochran & Conn, 2008); (d) decreased disability, anxiety, and health-care utilization; and (e) increased psychological well-being (Foster, Taylor, Eldridge, Ramsay, & Griffiths, 2007; Kennedy et al., 2007).

MSSM, as a theory, helps rehabilitation counseling professionals to understand the choices being made by rural individuals and, through education, gives the power for making self-management and treatment decisions to the individual. One potential issue particularly salient to individuals living in rural areas is how to access information pertinent to MS. Frequently, rural areas lack broadband services allowing community member to access the Internet, which is one of the most often cited methods for acquiring information. Additionally, because of the lack of specialty providers and the overreliance on primary care professionals to manage chronic illnesses, the potential exists for inadequate information. Rehabilitation counselors have both a charge and an opportunity to bridge the knowledge gap by providing guidance and information to rural residents. One important barrier to be addressed is getting health-care and illness-specific information into rural communities, which is addressed in detail in Chap. 29.

The SMSS model fits well with the belief systems that are prevalent in rural communities concerning the desire to be self-sufficient and the belief individualism regarding decisions about personal well-being. For this model to work in rural communities, rehabilitation counselors and other health professionals need to work collaboratively with people with MS using a person-centered approach. In order for persons with MS to self-manage their illness, they must first have the belief system and confidence they have the ability to control their life (Thompson, 2002). In rural communities, this belief system is generally in place; health-care professionals need to draw the parallels between taking care of their farm and taking care of their MS. Because rural citizens often think of health in more black and white terms of being able to work or not work, professionals should emphasize self-management to understand if one can work on a particular day or needs to rest. With a deeper understanding of the signs and symptoms of MS, people can gain confidence in what the body symptoms are telling them about the ability to do work. Over time, this higher level of perceived control over the illness has led to reduced anxiety and depression, better physical health, reduced impairment in daily living, higher levels of subjective well-being, and an increased likelihood that an individual will take action to improve or protect their physical health (Affleck, Tennen, Pfeiffer, & Fiffield, 1987; Bandura, 1997; Carver et al., 2000; Endler, Kocovski, & Macrodimitris, 2001).

Communication with Health-Care Provider

Rural communities are more likely to make a decision after receiving input from others who are involved in the situation. For people with MS, this means that important life decisions (e.g., staying at work, home health care, moving to assisted living) result from gathering information and opinions from significant others. These may, indeed, include a variety of health-care providers (e.g., primary care physician, physical therapist, occupational therapist, neurologist) and may include those with whom the individual has significant relationships. Deciding to be open with health-care providers regarding symptoms and limitations requires collaboration and trust by both parties involved. Past research has indicated that those who have a trusting relationship with their treatment team and are in agreement with the approach to treatment fare much better than those who have a more distant and skeptical relationship (Bishop & Frain, 2007). As a result of the heterogeneous and inconsistent course of MS, communication between patient and provider is essential. There is no one-size-fits-all treatment regimen for individuals with MS, but well-informed health-care professionals can more effectively advise individuals of potential challenges and prepare patients to address them. Ultimately, to be effective, acculturation of health-care providers into rural communities in an attempt to garner trust and assume to role as an insider will likely produce more productive collaborative care.

Treatment Adherence

Compliance with medical advice, like any decision, is personal, and individuals have a variety of reasons for opting to not adhere a provider's treatment plan. Adherence refers to the extent to which an individual follows the health-care professionals' orders/advice given to the patient such as diet, exercise, medications, and other health-care behaviors. One of the most widely researched topics concerning compliance addresses adherence to prescribed medications. According to the World Health Organization (WHO, 2003), improved treatment adherence would have a greater impact on health than most treatment advances. Research indicates that among non-MS treatment groups, medication adherence rates range from 25% to 50% Bosworth, 2006), and for individuals with MS, adherence ranges from 27% to 41% (Turner, Williams, Sloan, & Haselkorn, 2009). Clearly, nonadherence to treatment regimens may result in increased morbidity and decreased quality of life.

Reasons for treatment nonadherence vary greatly, but several common factors include (a) lower education, (b) increased disability, (c) perceived lack of efficacy, (d) lack of physician support, and (e) side effects (Bruce, Hancock, Arnett, & Lynch, 2010). Considering that individuals in rural communities have lower levels of education and there are fewer providers, one can understand why adherence may be even higher in these areas. A couple of factors not included in the previous list that certainly have an impact on adherence are medication costs and lack of health insurance. Again, incomes tend to be lower, on average, in rural communities, and due to higher rates of unemployment, fewer individuals have insurance coverage than those in urban areas. As previously described, openness with one's providers is critical to receiving appropriate care, and literature supports the positive correlation between individuals who are comfortable speaking candidly with their providers and treatment adherence (Bruce et al., 2010). Rural people with MS have expressed that the needs of their work, sometimes farm related, come before the need to take medication that may help in the long run. A frank discussion regarding the necessity of following a given treatment plan, why a certain medication was chosen, and ensuring that the individual understands the pros and cons is critical in an attempt to increase adherence and more positive outcomes.

Social Support

Social support includes the supportive input that people receive from his/her social environment. Social support generally addresses three basic needs of an individual – emotional, instrumental (e.g., helping), and informational (Krokavcova et al., 2008). Social support not only impacts treatment adherence and overall quality of life, it is well documented that rural culture affects the health-care behaviors and the environmental factors of health in rural health settings (e.g., Stein, 1982; Stein & Pontious, 1985). Geographical dispersity of individuals in rural communities has been cited as the main factor in whether people are able to self-manage their health conditions (Winters, Cudney, Sullivan, & Thusen, 2006). Although there is a paucity of resources available for individuals with MS who live in rural communities, social support remains ubiquitous. Many residents have developed long-standing relationships and have spent their entire lives in a community where helping one another is a deeply engrained moral imperative. Considering this, when an individual acquires a chronic illness or disability, which severely limits mobility, the geographic distance can severely affect one's ability to engage socially.

Social support encompasses many different areas in self-management of MS. Specifically, social support was one of the factors posited to be positively associated with self-management (Bishop & Frain, 2011). The family unit including spouses and other live-in caregivers can be instrumental to providing for the support needs of someone with MS. Peer support networks have also demonstrated to be beneficial in helping individuals obtain answers to questions and serving as a guide for symptoms and disease expectations. Peer support groups, in particular, may be limited in rural areas simply due to the lack of resources and low numbers of individuals diagnosed with MS.

Knowledge of MS

The stereotype of rural dwellers is they are industrious – when they have a problem they fix it and when they don't know how to fix something, they learn how. That spirit encompasses the very essence of self-management. Health literacy, the ability of people to gather, process, and make appropriate decisions regarding health information, is frequently discussed in extant literature, and its role in positive health outcomes is clear (Mackert, Ball, & Lopez, 2011). Knowledge about MS or any disease is one of the most empowering factors associated with positive outcomes. Considering the lower educational levels on individuals living in rural communities, achieving acceptable health literacy will take a concerted effort of all stakeholders involved in one's care. Additionally, low health literate individuals often find understanding a physician's explanation of their illness challenging, which results in poor health outcomes (Schillinger, Bindman, Wang, Stewart, & John, 2004). Because individuals may receive health information from a variety of sources, it is critical that providers be cognizant of those with low health literacy, provide clear interpersonal communication and readable and clearly understood handouts, and allow extended time to answer all questions (Mackert et al., 2011).

Although individuals with MS are considerably underrepresented in the public vocational rehabilitation system, research indicates that rehabilitation counseling professionals should encourage and guide people with MS on how to find out about their situation and do research themselves. Neurologists are a great resource, but they are busy. People with MS need to become proficient at using the Internet to find information and talking to others in an attempt to become more knowledgeable about MS and its symptoms.

Although individuals with MS are significantly underrepresented in the public vocational rehabilitation system, evidence supports its effectiveness at increasing employment outcomes. One way to increase vocational rehabilitation utilization is through dissemination of information. Providers need to be aware of what services are offered and how his/her patients can benefit from them. Upon meeting with a rehabilitation counselor, the counselor's role is to assess the client's health literacy and provide him/her with information and resources to help guide the client's decision-making process.

Discussion Box

We have discussed the complexities associated with MS and the challenges related to assisting diagnosed individuals to maintain an active and participatory lifestyle. MS results in physiological, psychological, and emotional difficulties that significantly affect one's ability to interact socially and maintain employment. In rural communities, these sequelae become even more challenging to adequately address. Frequently, there is a lack of both primary care and specialty providers, ancillary professionals (e.g., PT, OT, counseling) are scarce, fewer employment opportunities exist, limited transportation options preclude commuting to adjacent communities for work, and obtaining quality information is difficult. Although there are evidence-based practices available for treating individuals with MS, implementation in rural areas may not be reasonable. Moreover, rehabilitation counselors who cover rural communities encounter extreme geographic barriers that may negatively affect time spent with consumers, and developing relationships with employers across broad distances may prove challenging.

1. Besides the aforementioned challenges, what other concerns does an individual with MS living in a rural area present?
2. In areas with limited employment options, what are some possible solutions that may be feasible?
3. What are possible means of getting MS information to those living in rural areas?

Health Maintenance Behavior

Health-promoting behaviors, namely, exercise and other physical activity, have been espoused to have a positive impact on improving functional limitations and quality of life (Debolt & McCubbin, 2004). One has little control regarding the course of MS, but physical activity is an area where individuals have significant control, which can substantially alter outcomes. As a result of the sequela (e.g., depression, fatigue) of MS, individuals frequently struggle to continue an active lifestyle and become increasingly isolated, which exacerbate symptoms. Helping individuals understand that physical activity is an evidence-based intervention demonstrated to produce positive outcomes. In fact, in longitudinal research by Stuifbergen, Blozis, Harrison, and Becker (2006), more frequent exercise behaviors among individuals with MS was associated with lower functional limitations and improved quality of life.

Promoting health maintenance behaviors in rural areas fits with the research on rural beliefs about health by allowing individuals to maintain some degree of control of their lives (Weinert & Long, 1987). Part of the rehabilitation counselor's role is to assist clients in understanding the benefits of exercise and to motivate them to take an active role in the management of their illness. Moreover, through an interdisciplinary approach, helping rural individuals with MS to find physical activities that fit within the context of their functional limitations is essential for positive long-term effects.

MS Health and Symptom Awareness

Although many of the symptoms associated with MS are commonly experienced, having an understanding of which symptoms are MS-related and which are not is often challenging. Self-awareness is viewed as the ability to recognize problems related to impairment (Goverover, Chiaravalloti, Gaudino-Goering, Moore, & DeLuca, 2009). People with MS need to become aware of actions that can be taken to reduce symptoms and to listen to their bodies for signs that rest may be necessary. Furthermore, becoming more self-aware of how MS affects one's body can give individuals a sense of control over appropriate management interventions. It seems reasonable that someone with high self-awareness might recognize symptoms earlier or perhaps experience them as more intense and, therefore, be better equipped to monitor ongoing symptoms and "cope" with them better, experiencing them as less problematic, as compared to someone who is not highly self-aware.

Following one's diagnosis of a chronic medical condition, individuals go through varying stages or phases of acceptance and adjustment. During this time, they begin to pay attention to what changes are taking place in their bodies and typically report them to their providers. Throughout the adjustment phases, individuals will likely benefit from information from professionals that highlights potential changes and symptoms of the illness. In rural communities where specialty providers are scarce, individuals may not have access to complete information about their condition resulting in poor understanding about symptoms and their effects on functioning. Not all clients or patients need help knowing what symptoms to avoid and how best their body works, but many will. For those in need, training on recognizing symptoms and questions to ask their

Case Study

Kimberly is a 32-year-old female who was diagnosed with relapsing-remitting MS at the age of 28. Kimberly is unfamiliar with MS and its course and is not sure what symptoms she needs to be concerned with. She has 7 years of experience working as a receptionist at a local business but recently quit her job due to the perceived exacerbations of MS. She has experienced extreme fatigue, depression, and pain. She no longer drives as a result of the pain medication that her family doctor prescribed. She is not currently taking any disease modifying drugs to treat her MS and has relapses every couple of months. She has stopped participating in social activities and feels lonely. She set up a meeting with the office of vocational rehabilitation to discuss her employment options but had to wait nearly 2 months to actually meet with a counselor. Following her meeting, the counselor ascertained that Kimberly's depression and fatigue were the key factors needing to be addressed prior to resuming employment. Additionally, the counselor believed that PT and a neurology consult would be prudent. Kimberly lives about 2 h from the closest major city, which is where the neurologist practices. There are no PTs in her city to help with her mobility.

1. What are some possible options for the rehabilitation counselor to consider to assist Kimberly?
2. What type of job accommodations needs to be considered for Kimberly if she returns to work?
3. Where can the rehabilitation counselor find information to help Kimberly understand her disease course?

health-care professionals can be helpful for shaping their future activities and vocational choices.

Summary

Multiple sclerosis is a chronic condition that results in substantial changes to one's physiological, psychological, and emotional abilities. Functional challenges are common, which have a detrimental effect on overall perceived quality of life. Although there is no cure for MS, there exist a number of effective disease-modifying drugs along with interventions aimed at improving individuals' participation in important areas of life. Rural areas come with substantial challenges in effectively affording individuals with MS available options for quality care (e.g., lack of providers, unavailable transportation options). Professionals working with individuals in rural communities need to be aware of the numerous challenges and take efforts to ensure that individuals with MS have access to information about their illness, symptoms, and potential activities (e.g., exercise, peer support, social support) that may improve functioning. Considering the paucity of research addressing the potential barriers to care for people with MS in rural communities, additional research is warranted.

Resources

National Multiple Sclerosis Society: http://www.nationalmssociety.org

WebMD – Multiple Sclerosis: http://www.webmd.com/multiple-sclerosis/guide/multiple-sclerosis-support-resources

Overcoming Multiple Sclerosis: https://overcomingms.org/ms-a-to-z/resources/

MSLifeLines: http://www.mslifelines.com/what-is-ms?cmp=M_MS+Core_Misspelling%20MS_Phrase_multiple_sclerosi_Bing_PS&utm_source=google&utm_medium=cpc&utm_campaign=MS%2BCore&utm_content=Misspelling+MS_Phrase&utm_term=multiple+sclerosi

U.S. Department of Veteran Affairs: https://www.va.gov/MS/Veterans/resources/index.asp

PubMed Health: https://www.ncbi.nlm.nih.gov/pubmedhealth/PMHT0024311/

AboveMS: https://www.abovems.com/en_us/home/team/healthcare-team/psychological-support.html?cid=ppc-bng-unbranded-lifestyle-na-41685-unbranded_lifestyle

MultipleSclerosis.net: https://multiplesclerosis.net/living-with-ms/dealing-with-ms-diagnosis/

Learning Exercises

1. Describe the common symptoms associated with MS that affect employment.
2. What are some challenges that need to be addressed along the continuum of seeking employment?
3. What are possible solutions to unavailable transportation?
4. What can rural communities do to attract adequate professionals?

Field-Based Experiential Assignments

1. Meet with or call a rehabilitation counselor who covers rural communities, and ask about their challenges in providing services to clients.
2. Talk with a specialty provider (e.g., neurologist, PT) to discover what they perceive to be the greatest barriers to employment for individuals with MS.
3. Look up a rural area and develop a list of providers who would be important for an individual with MS.
4. Attend a local MS support group to gain the perspective of the client.

Multiple Choice Questions

1. How many individuals are estimated to have MS in the worldwide?

   - (a) 5 million
   - (b) 2.3 million
   - (c) 3.2 million
   - (d) 1.7 million
2. What is the average age of MS onset?
   - (a) 30–40
   - (b) 50–60
   - (c) 20–30
   - (d) No specific age because it varies greatly
3. Which of the following is positively associated with living in a rural community?
   - (a) Transportation
   - (b) Employment options
   - (c) Access to health care
   - (d) Social support
4. What is the reported average medication adherence rate for individuals with MS?
   - (a) 27%–41%
   - (b) 10%–21%
   - (c) 45%–60%
   - (d) 71%–83%
5. Individuals with MS are ______ in the public vocational rehabilitation system.
   - (a) Overrepresented
   - (b) Underrepresented
   - (c) Normally distributed
   - (d) Not typically served due to order of selection
6. Which of the following is *not* a perceived benefit of individual self-management?
   - (a) Increased perceived control over illness
   - (b) Decrease in hospitalizations
   - (c) Increased quality of life
   - (d) Improvement in employment outcomes
7. Of the unemployed individuals with MS, what percentage report they would like to return to work?
   - (a) 50%
   - (b) 75%
   - (c) 35%
   - (d) 90%
8. MS is the ___________ nontraumatic cause of nervous system disabilities in young adults.
   - (a) Second leading
   - (b) Third leading
   - (c) Leading
   - (d) Fourth leading
9. It has been estimated that within 10–15 years of an initial diagnosis of MS, approximately __________ of patients will experience some degree of impaired mobility.
   - (a) 50%
   - (b) 25%
   - (c) 100%
   - (d) 80%
10. What is MSSM?
    - (a) Mobility and Social Security Measure
    - (b) Multiple Sclerosis Stress Measure
    - (c) Multiple Sclerosis Self-Management
    - (d) Multiple Social Support Measure

Key

1. B
2. C
3. D
4. A
5. B
6. D
7. B
8. C
9. D
10. C

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28

Substance-Related and Addictive Disorder Treatment in Rural, Frontier, and Territory Settings

Debra A. Harley and Byung Jin Kim

Overview

Substance-related and addictive disorders (SRAD) are highly prevalent in the United States and continue to increase each year. Doweiko (2015) suggests, "in a sense illicit drug use might be said to be an American way of life" (p. 3). However, regardless of the country of origin, some of the contributing factors to SRAD in rural, frontier, and territory (RFT) communities are isolation, poverty, and unemployment, as well as differences in the availability and accessibility of prevention and treatment resources (Council on Drug Abuse, 2004). The isolation of rural areas makes it easier for grow operations (grow-ops) and drug labs to establish and to operate without detection. In fact, rural areas have been susceptible to methamphetamine producers and traffickers because of limited and financial resources for law enforcement; wide, open spaces which make production harder to detect; and easy access to ingredients (Kraman, 2004). Drugs are chemicals, and chemical agents and structures can affect the body in different ways. Drugs can alter the brain and body in ways that cause long-lasting effects even after drug usage has stopped. These effects can be temporary or permanent. SRADs result in direct and indirect costs to society in terms of healthcare costs, lost work productivity, family disruption, child abuse, domestic violence, accidents and motor vehicle crashes, interpersonal violence, crime, homicide, suicide, physical and psychological impairments, human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), sexually transmitted diseases (STDs), and death (US Department of Health and Human Services, 2010).

For many decades, rural areas were more sheltered from the problems of mainstream America, but technology has decreased the isolation of rural and very rural areas (Schoeneberger, Leukefeld, Hiller, & Godlaski, 2006). The implication suggested by Schoeneberger et al. is that some of the problems that occurred mainly in urban areas and larger communities have infiltrated into rural areas because technology, and the resulting connectedness, has been able to bring them to these areas. The persistent stereotypes about rural areas being unaffected by drugs and crime have contributed to misperceptions that have resulted in a lack of social, health, and substance abuse data in these communities (Kraman, 2004). Unfortunately, many stereotypes about rural communities are related to barriers to treatment.

This chapter is designed to provide the reader with background information about substance-related addictions and how certain issues impact

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D.A. Harley (✉)
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: dharl00@email.uky.edu

B.J. Kim
University of Kentucky, ESDRC Department, Lexington, KY, USA
e-mail: byungjin.kim@uky.edu

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rural areas. The reader is reminded that the term rural is used through this chapter as inclusive of rural, frontier, and territory communities.

Learning Objectives

Upon completion of this chapter, the reader should be able to:

1. Identify the prevalence and problems of substance abuse and addiction in rural, frontier, and territory communities.
2. Identify patterns of substance abuse and addiction in rural, frontier, and territory communities.
3. Identify barriers to substance abuse treatment in rural, frontier, and territory communities.
4. Understand the collateral consequences of substance abuse in rural, frontier, and territory communities.
5. Describe counselor-related issues to working with addiction problems in rural, frontier, and territory communities.

Introduction

For a long period of time, researchers and policymakers in the United States focused their attention almost exclusively on the drug problem in urban areas (Schoeneberger et al., 2006). Historically, the prevalence of substance abuse in rural communities compared to urban areas has been lower. In general, urban areas had higher rates of illicit drug abuse, and rural areas had higher rates of alcohol abuse (Lenardson & Gale, 2008). Over time, the line that distinguished the type of substances abuse across geographic locations has diminished. According to Falck et al. (2007), "non-medical drug use in rural communities in the United States is a significant and growing public health threat" (p. 107). Drug abuse, especially of heroin, methamphetamine, and prescription medication, has reached epidemic proportion in rural communities (Keyes, Cerda, Brady, Havens, & Galea, 2014). Research is available on estimations of the percentage of persons addicted to particular types of substances; however, these figures are deceptive because of cross addictions and polysubstance abuse (Doweiko); accuracy of reporting of illegal drug use; omission of substances that are identified as less relevant such as tobacco, nicotine, and caffeine; and medical versus nonmedical use of psychotherapeutic drugs and pain medication and the often overlooked abuse of steroids. For example, approximately 24 million Americans aged 12 and older require treatment for a substance abuse issues, yet only about 11% receive treatment at a specialty facility (National Institute on Drug Abuse, 2011). Yet, other figures suggest even lower access at 10.2% for illegal drug users in 2014 (Centers for Disease Control, 2016a). Next, consideration has to be given to differences based on age, gender, and ethnicity. In fact, Fisher and Harrison (2013) indicate "it is almost trite to recite the problems related to the use of alcohol and other drugs in our society," and "the array of graphs, percentages, and dollar amounts" provide an avalanche of data to document that substance abuse and its consequences are serious problems in the United States (p. 1). For those reasons, this chapter will not delve deeply into providing statistics; rather, we will focus on more descriptive content.

Biglan et al. (1997) suggested several issues that must be kept in mind in a discussion about substance-related and addictive disorders. First, they are intertwined with other problem behaviors. Second, substance abuse and addiction stem from a complex set of social context factors. Third, treatment intervention is only one component in substance abuse problems and should be combined with educational and prevention strategies to mobilize and refocus existing elements of the community to address addiction problems. Finally, SUD is recognized as a disease, implying that it is diagnosable and treatable (*Diagnostic and Statistical Manual of Mental Disorders* [DSM-5], 2013).

Characteristics of Persons with Substance-Related and Addictive Disorders in Rural Areas

Substance abusers in rural areas expand across the age continuum from youth/adolescents to adults and the elderly and vary in types of substances used. However, rural abusers that enter treatment are different than urban abusers in several ways: (a) rural admissions were younger and less racially and ethnically diverse, (b) rural admissions were more likely than urban admissions to report primary abuse of alcohol or non-heroin opiates, and (c) rural admissions were more likely than urban admissions to be referred by the criminal justice system (Substance Abuse and Mental Health Services Administration [SAMHSA], 2012). Urban and rural admissions had similar gender distribution, with male representing over two-thirds of admissions for both. SAMHSA (2012) also reports that rural and urban admissions differ in educational attainment with rural individuals being more likely to have a high school education or GED and be employed and urban individuals were more likely to have less than a high school education. Urban and rural admissions differ in their rate of use; urban were twice as likely to report daily use of their primary substance. Rural and urban admissions reported similar rates of co-occurring psychiatric disorders. Finally, urban admissions were almost five times as likely as rural to be homeless.

Rural communities are less likely to proactively address substance abuse and addiction problems. According to Gundy (2006), one of the strengths of rural communities can also serve as a barrier to seeking treatment. Typically, residential stability and a strong sense of community lead to a stronger support network in rural areas than in urban areas; close-knit communities often discourage help from "outsiders." In addition, rural families are more reluctant to use treatment service; the family strives to maintain secrecy and privacy about a member who has substance-related and addiction problems, and stigma exists around the need for treatment (Gundy; Rural Health Information Hub, n.d.). In frontier areas, such as Montana, the substance/alcohol abuse rate is nearly one-and-a-half times the national average, with youth drug/alcohol use beginning on average at age 13 (National Disability Navigator Resource Collaborative, NDNRC, 2014). The three most common challenges addiction counselors across the region face are universal in rural areas: (a) distance clients had to travel for services, (b) the young age at which Montanans begin using alcohol and drugs, and (c) the independence of individuals that prevents them from seeking help (NDNRC). When substance abusers in isolated rural areas do go to treatment, they are referred to counseling and self-help groups, implying a greater reliance on less intensive treatment settings (Lenardson, Race, & Gale, 2009).

A related issue to substance abuse in rural, frontier, and territory communities is domestic violence (DV) and intimate partner violence (IPV) (Bennett & Bland, 2008). Although men and women can be victims of DV and IPV, overwhelmingly women are victims and men are perpetrators. Logan, Walker, Cole, Ratliff, and Leukefeld (2003) found that women in rural areas are more likely to be married to their abuser and tend to have been in a relationship with the perpetrator longer than urban women. Cultural expectations common to rural communities and patriarchal views of the family and the role of women, the permanence of marriage and religious beliefs, and beliefs of female subservience tend to establish IPV as a normative behavior (McCall-Hosenfeld, Weisman, Perry, Hillemeier, & Chuang, 2014; Riddell, Ford-Gilboe, & Leipert, 2009). Although domestic violence occurs at similar rates in urban and rural areas, it is a lower priority in rural areas (suggested by the low rates of success in serving protective order petitions; fewer charges, prosecutions, and convictions in domestic violence crimes; and the perception by female victims that they have less access to protective orders and enforcements) (Logan, Walker, Hoyt, & Faragher, 2009). In addition, perpetrators in rural areas have the benefit of the "good ole boy" system, in which they know and are known by local law enforcement and, because of this association, they are not subject to legal consequences (Rural Survivors and Economic Security, 2013). The National Federation of Women's Institutes reported that rural and urban women were equally likely to be victims of violence, but rural women were less likely to think of it happening (McCarry & Williamson, 2009). Moreover, rural women were less likely to report violence because of shame, fear, or threats.

Violence may occur over substance use or ending use, in the process of obtaining and using substances, being forced to use substances with her or his abuser, or using substances with her/his abuser in an attempt to manage the violence and increase her/his safety. Often, rural women are prevented from leaving the relationship or from seeking help because their abuser controls the transportation and communication channels (Peek-Asa et al., 2011). Rural poverty is also highly correlated with DV and IPV.

Frequently, the involvement of law enforcement in DV and IPV situations uncovers the presence of substance abuse problems. Otherwise, understaffed law enforcement entities are often spread too thin to cover vast land mass and sparsely populated areas in RFT communities, resulting in substance abuse problems going undetected and being addressed after-the-fact through the criminal justice system (Carsey Institute, 2006). The limited experience of rural first responders or rural hospital emergency room staff in providing care to a patient presenting the physical effects of a drug overdose may further exacerbate the challenges rural communities face in addressing substance abuse and its consequences (Rural Health Information Hub, n.d.), as well as making a connecting between DV, IPV, and substance abuse. One other factor in combination with violence and abuse when considered within the context of rural communities is age. With a higher share of persons aged 65 and older living in rural areas, service providers who work closely with the elderly would benefit from training in recognizing and responding to the emotional effects of IPV (National Advisory Committee on Rural Health and Human Services, 2015).

Risk factors Risk factors are those issues that contribute to the person engaging in substance use or abuse. Persons with disabilities and/or rural residents with and without disabilities have risk factors for substance abuse. Some of these risks are interrelated, and others may be related specifically to certain age groups, racial or ethnic groups, gender, or disability group. Also, risk factors may not be mutually exclusive from barriers to treatment. Risk factors include geographic isolation, limited social networks, substance use at an early age, low educational attainment, low religious commitment, levels of adult and/or peer substance use, and parental and/or peer approval of substance use (Gale, Lenardson, Lambert, & Hartley, 2012). Other risk factors that are specific to rural adolescents are being an older adolescent (i.e., aged 15 years or older), spending time after school with friends or engaged in leisure, having friends or family members who use substances, being raised by nonfamily members, having pans to enter the military after school, and having limited educational plans (Myers, 2012). Peer influence was associated with greater substance use in rural areas but was moderated by adolescents' social network, specifically the extent to which adolescents associated with peers who respect parents, teachers, and authority figures avoid getting in trouble (Gale et al., 2012). Poverty, domestic violence, and unemployment are risk factors for women in rural areas. For many rural residents, depression, employment and financial issues, and cultural stereotypes may pose increased risk for substance abuse.

Keyes, Cerda, Brady, Havens, and Galea (2014) attributed the growing problem of nonmedical prescription opioid misuse in rural areas to four sources. First, the greater number of opioid prescriptions provided to residents in rural areas creates availability from which illegal markets can arise. Second, an out-migration of young people leaves many areas desolate in terms of economic conditions (discussed later in this chapter). Also, out-migration has a selection effect on young adults that stay, resulting in a greater accumulation of risk factors for problematic drug use and more likely to have established drug dependencies at a young age that cause downward social drift. Third, the existence of greater rural social and kinship network connections may facilitate drug diversion and distribution. Finally, economic stressors may create vulnerability to drug use more generally. These authors suggest "a systematic consideration of the contexts that create differences in availability, access, and preferences is critical to understanding how drug use context varies across geography" (p. e52). Keyes et al. used the ecosocial theory (Gaela, Ahern, & Vlahov, 2003; Krieger, 2001) and ecological systems theory (Bronfenbrenner, 1979) to explain risk factors that drive illicit drug use and organized them by three levels of influence. Level 1 is the macrolevel in which the social context structures the availability of drugs and the norms around used. Level 2 is the local level, which includes family dynamics, family composition, and family stress, and peer influence is strongly correlated with drug use. Level 3 is the microlevel in which endogenous factors such as genetic vulnerability, neurobiological factors, pharmacological reactivity, personality traits, psychiatric morbidity, and gender and age have strong influences on the propensity to misuse drugs and develop chronic drug dependencies (Keyes et al., 2014).

There are a number of contributors to increased risk of substance-related and addiction disorders. These risks can be divided into five categories: health and medical, psychological, interpersonal and social, economic and employment, and access (Brucker, 2007; West, Graham, & Cifu, 2009) (see Harley, Bishop, and Tiro (2016) for discussion of these risk factors). Other risk factors for people with disabilities include pain, access to prescription pain medication, chronic medical problems, depression, social isolation, enabling by caregivers, unemployment, limited education, low socioeconomic level, little exposure to substance abuse prevention education, and a history of physical or sexual abuse (SAMHSA, 2011a; Wolf-Branigin, 2007). Although persons with intellectual and developmental disabilities (IDD) have a lower prevalence for substance abuse, they are at an elevated risk for experiencing a substance-related or addictive disorder, especially if there is an association between the severity of IDD and substance use spectrums, as problematic substance use increased with cognitive function (Didden, Embregts, van der Toorn, & Laarhoven, 2009). Individuals with other types of disabilities that are disproportionately affected by SUD are those with traumatic brain injury (TBI), spinal cord injury (SCI), multiple sclerosis (MS), and mental health disorders. Bombardier et al. (2004) found that persons with MS may be at greater of substance abuse because of the potential magnification of motor and cognitive impairment, as well as contributes to high rates of depression. For persons with SCI, daily alcohol consumption and, for those with TBI, illicit drug use tend to be higher post-injury (Kolakowsky-Hayner et al., 2002). In some studies, both TBI and SCI are associated with a higher rate of post-injury versus pre-injury. In other studies, rates of pre- and post-injury substance abuse among TBI and SCI groups equate to substantial numbers of individuals in need of substance abuse treatment (Langlois, Rutland-Brown, & Thomas, 2004; National Spinal Cord Injury Statistical Center, 2008). Overall, persons with disabilities who have substance abuse and addictive disorders abuse substances at higher rates than persons without disabilities. Further PWD have higher rates of isolation and reduced socialization and have increased risk for abusing AOD (Brault, 2012; SAMHSA, 2013).

Patterns of use In a study of drug use patterns and trends in rural communities, Gfroerer, Larson, and Colliver (2007) examined the prevalence of tobacco, alcohol, and illicit drug use among adolescents and adults in three types of counties: rural (nonmetropolitan with urban population less than 20,000), urbanized nonmetropolitan (nonmetropolitan with urban population 20,000 or higher), and metropolitan (metropolitan areas). The authors found illicit drug use is generally similar among adolescents in rural, urbanized nonmetropolitan, and metropolitan counties, with the exception of ecstasy use being higher among metropolitan and urbanized nonmetropolitan youth. Rural youth have a higher prevalence of stimulant and methamphetamine use. Rural adults had generally lower rates of illicit drug use than metropolitan adults, but adults in rural and urbanized nonmetropolitan areas had higher rates of methamphetamine use than those in metropolitan areas. Both rural youth and adults had higher prevalence of tobacco use, and rural adult had lower rates of alcohol use while youth had higher rates.

Gfroerer et al. concluded that the results dispel the notion that substance abuse is only an urban problem and that the unique characteristics of rural residents need to be considered in developing and implementing interventions. Inhalant abuse exists in both urban and rural areas, and studies reveal that girls are using inhalants at higher rates than boys (Mosher, Rotolo, Phillips, Krupski, & Stark, 2004).

Other studies that examined substance abuse among rural youth found similar results to those of Gfroerer et al. (2007). Hartley (2007) found young adults in the smallest rural areas use methamphetamine as a rate that is nearly twice that of young urban adults. Furthermore, this pattern is similar for prescription pain relievers. In addition, rural youth from the smallest areas are more likely to consume alcohol and to engage in binge drinking (five or more drinks on a single occasion), heavy drinking (binge drinking on five or more occasions over a period of 1 month), and driving under the influence than urban youth, and almost half of young adults in larger rural areas have engaged in binge drinking. Hartley considers these numbers significant because the smallest communities have the least resources to prevent and to treat these substance problems and because as youth in rural areas become young adults, they have easier access to alcohol and to motor vehicles. An earlier study by Gundy (2006) found similar results in which alcohol use among rural youth exceeded that of urban youth and abuse of alcohol is elevated among rural youth. With the exception of methamphetamine, the level of illicit drug use is lower than alcohol use for youth in rural communities and is equally concerning. The Gundy study also found several other significant findings. First, the gap between rural and urban methamphetamine use has widened, with rural use sharply increasing and urban use decreasing. Second, unemployment status was an especially important factor for methamphetamine and other stimulant abuses among rural residents. Unemployed rural residents were approximately seven times more likely than unemployed urban residents to abuse stimulants. Finally, educational level is more closely correlated to illicit drug abuse rates in rural areas, especially among young adults who demonstrated increased levels of drug abuse as levels of education decreased. The only exception in which educational attainment did not have any effect on decreasing drug use between urban and rural was with stimulant use.

Comparatively, age is a contributing factor to illicit drug use between rural and urban populations. The client population in rural areas is getting younger, which has an impact on levels of care across the continuum, as well as grave consequences. The effects of drug use on brain development of younger individuals are significant. According to the Centers for Disease Control and Prevention (2016b), people in rural communities are more likely to overdose on prescription pain medications than people in cities, and the rate of opioid-related overdose deaths in nonmetropolitan counties is 45% higher than in metropolitan counties. Clearly, the drug abuse landscape in rural areas has changed considerably over the last decade, and heron-, fentanyl-, and opioid-related deaths have quadrupled since 1999 (CDC, 2016b). Rates of drug overdose deaths were highest among the states of West Virginia (35.5 deaths per 100,000), New Mexico (27.3), New Hampshire (26.2), Kentucky (24.7), and Ohio (24.6) (Rudd, Aleshire, Zibbell, & Gladden, 2016).

Gundy (2006) indicates that states with the highest rates of youth alcohol abuse have the greatest unmet need for treatment. In addition, these states also have large rural populations. An explanation for the higher rate of nonmedical prescription drug use among adolescents is their lower perceptions of harm. According to Johnson, O’Malley, Bachman, and Schulenberg (2010), adolescents perceive prescription opioids (e.g., OxyContin, Vicodin) as more harmful than other prescription drugs such as Adderall and amphetamines, but they perceive prescription opioid use as less harmful than the use of almost all other drugs except experimental alcohol and occasional marijuana use. These lower perceptions of harm for prescription opioids compared to other illicit drugs can be because of two factors. One, opioid use for pain management is commonplace, and nonmedical users observe this in their familial and social networks. Two, prescription opioid use (as intended) does not have routes of administration with higher social stigma such as smoking, snorting, and injecting.

Economics and employment Substance abuse and addiction are both influenced and impacted by economics and employment status of rural areas. During the recession, rural areas were disproportionately disadvantaged and had less economic recovery than urban areas. Both adverse economic conditions and high rates of unemployment have contributed to greater vulnerability to substance-related and addiction problems among rural residents, especially those who are disenfranchised, poor, minority, or less educated. Unemployment was found to be an especially important factor for methamphetamine and other stimulant abuses among rural residents (Grundy, 2006). Also, closely aligned with high unemployment in rural areas is homelessness. Although homelessness is less common in rural than urban areas, rural homelessness is estimated at 7% (National Alliance to End Homelessness [NAEH], 2010). Factors contributing to rural homelessness include insufficient income and high rates of poverty and increasing housing costs concurrently with declining industries such as farming, mining, timber, or fishing. Addressing rural homelessness is more difficult than in urban areas because of a lower capacity in the homeless service provider infrastructure (NAEH).

While the rural economy has become more diverse (e.g., services, government, manufacturing), it faces a number of unique challenges regarding its labor force in comparison to urban areas (Council of Economic Advisors, n.d.). The first is incomes are lower and poverty rates are higher. Second, a lower proportion of the rural population is of working age (20–64), which presents challenges for future job creation. Keyes et al. (2014) suggest that out-migration of young people from rural areas left an aging workforce in place, which yields less new economic infrastructure in rural areas. Third, a higher portion of rural residents are on disability and therefore unable to participate in the rural workforce. Fourth, educational attainment lags behind that of urban areas for the working-age population (Council of Economic Advisors) (see Chap. 1 for more information on economic development and occupational outlook in rural area and Chap. 2 for discussion on poverty).

Barriers to Treatment

Barriers to treatment exist for both urban and rural substance abusers; however, the extent to which they are advantaged or disadvantaged differs. In the area of substance abuse treatment, one factor that can substantially impact the type of services offered and service utilization is population density (Agency for Healthcare Research and Quality, 2011; Lenardson & Gale, 2008). Urban treatment facilities are advantaged in that they offer a more diverse array of options for treatment and are more likely to provide auxiliary services (e.g., detoxification, mental health services) essential for successful outcomes, and urban counselors have more resources for specific types or diverse clients (e.g., ethnic minorities, women, HIV-positive populations, LGBTQ persons) (Pullen & Oser, 2014; SAMHSA, 2011b). However, because of decreases in population size in rural communities, an increasing number of substance abuse treatment facilities offer a combined focus on mental health and substance abuse treatment (Lenardson & Gale, 2008).

In urban and rural areas, substance abuse treatment facilities provide core substance abuse services: intake, assessment, referral, and substance abuse treatment. As the location of the facility becomes more rural, a significantly lower number of facilities provide specialized services such as detoxification, day treatment, methadone treatment, and transitional housing. In fact, nearly all of the opioid treatment programs (OTPs) are located in urban areas. Usually, the level of intensity of treatment is categorized as outpatient and inpatient/residential. Overwhelmingly, rural facilities provide regular outpatient services and far fewer inpatient and residential beds compared to urban areas (Lenardson & Gale, 2008).

Detoxification Detoxification (detox) services are considered to be one of the most important components in the treatment of substance abuse because it serves a gateway to longer-term treatment (Lenardson et al., 2009). Detox is the first stage of addiction treatment for persons requiring safe management of the acute physical symptoms of withdrawal while managing the medical complications and/or physical harm associated with stopping substance use (Lenardson et al., 2009; Stevens & Smith, 2013). It is important that the substance abuser, counselors, and family members recognize that detox should not be considered an end in itself (Stevens & Smith, 2013). The American Society of Addiction Medicine (ASAM) (www.asam.org/quality-practice/guidelines-and-consensus-documants/the-asam-criteria/about) defines one national set of criteria for providing outcome-oriented and results-based care in the treatment of addiction and is the most widely used and comprehensive set of guidelines for placement, continued stay, and transfer/discharge of patients with addiction and co-occurring conditions (Mee-Lee, 2013). The ASAM's six dimensions of assessment for service planning and care across all services and levels of care are:

1. Acute intoxication and/or withdrawal potential – exploring an individual's past and current experiences of substance abuse
2. Biomedical conditions and complications – exploring an individual's health history and current physical condition
3. Emotional, behavioral, or cognitive conditions and complications – exploring an individual's thoughts, emotions, and mental health issues
4. Readiness to change – exploring an individual's readiness and interest in changing
5. Relapse, continued use, or continued problem potential – exploring an individual's unique relationship with relapse or continued use or problems
6. Recovery/living environment – exploring an individual's recovery or living situation and the surrounding people, places, and things

In addition, a continuum of care consisting of five broad levels (ranging from 0.5 for early intervention to 4.0 for medically managed intensive inpatient services) is used with benchmarks along a continuum to express gradations of intensity of services. Patients can move up or down in terms of intensity without necessarily being placed in a new benchmark level of care.

The limited number of rural treatment facilities that offer detox services serves as a barrier to treatment in rural communities. Of the detox facilities in rural areas, many do not offer the full complement of recommended detox services. Furthermore, several issues may impede access to detox services in rural areas. One such barrier is lengthy travel distances. According to Lenardson et al. (2009), most detox providers have a service radius of at least 50 miles and often greater than 100 miles. Within the service radius, detox providers may be the only source of that service for their communities. The distance to detox facilities may have the added barrier of transportation for the rural resident (see Chap. 3 for discussion on transportation barriers). Rural detox facilities are further disadvantaged because they tend not to offer program or groups for special populations (e.g., adolescents, persons with co-occurring disorders, LGBTQ persons, the elderly, women, persons with development or learning disabilities, persons with sensory disabilities) (Lenardson et al., 2009).

Wait time Accompanying barriers to travel distance to detox facilities are access related to wait time, denial of admission, and lack of referral options (Lenardson et al., 2009). Each of these can be detrimental for substance abusers, particularly of opioids, because of the risk of overdose. Sometimes, an overdose is not necessarily from premeditate abuse but rather from mixing of prescribed pills for various conditions all at once. Usually, the result of overdose is a higher death rate in rural areas because emergency response times are longer (Rural Health Information Hub, n.d.). The amount of time a client has to wait for service is complicated further by others that do not show up for appointments, which negatively impacts clinical outcomes and healthcare productivity (Molfenter, 2013). Studies found that the effects of wait times on clients can contribute to dropout before treatment, unhealthy drug-using behaviors (e.g., needle sharing), and involvement in the criminal justice system. For some clients, it is not unusual to be on multiple wait lists because they are receiving services from other agencies (Pascoe, Rush, & Rotondi, 2013). The study by Pascoe et al. was conducted in Ontario, Canada, and found the exceptions for which a client can bypass wait times and be directly admitted into treatment included those at risk for harming themselves, pregnant women, people with personal safety issues or serious mental health problems, homeless individual, and those with concurrent disorders. In another study in the United States, participants identified three major themes relative to wait time as barriers. The first occurred between calling for an assessment appointment and actually receiving the assessment. The second was after assessment but before treatment entry. The third was strategies they developed to cope with wait time. The effect on their substance use during wait time varied, with some participants continued to use drugs for different periods of time; others managed to reduce their drug use, and others became abstinent – some still believed they needed treatment, and some began to question the need for formal treatment (Redko, Rapp, & Carlson, 2006). Both failure to show for appointments and not returning for a second appointment are prevalent in addiction treatment settings (Mitchell & Selmes, 2007).

Cost For many rural residents, being able to pay for substance abuse treatment is a barrier, especially if there is a lack of payment options, and the individual has limited financial resources. Lenardson and Gale (2008) found no major difference in the proportion of rural and urban facilities offering free treatment or that accept cash or self-payment. Because cost of treatment may be prohibitive for many rural residents, a greater proportion of rural facilities offer a sliding fee scale. In addition, more rural than urban facilities accept a variety of payment sources including Medicare, Medicaid, private health insurance, state health plans, and military coverage. However, "the Medicare and Medicaid reimbursement systems also pose a problem for rural residents because these areas are often unable to match federal dollars" (Kraman, 2004, p. 9). In the implementation of the Affordable Care Act (ACA) and development of ACA insurance plans, individuals seeking treatment for substance abuse and addictions should have expanded options and access to treatment. At the writing of this chapter, the future fate of ACA is unknown because of political efforts to repeal the act. Thus, the discussion in this chapter is based on the existing purpose and interpretation of the ACA. The ACA includes substance abuse disorder care among coverage stipulations. Although the existence of the ACA has increased access to treatment for substance abuse for Medicaid beneficiaries, it has not solved the problem of availability. Many treatment facilities do not have beds or room to accommodate the number of persons seeking treatment. In addition, federal restrictions on facilities with more than 16 beds cannot bill Medicaid for residential services provided to low-income adults. The intent of the federal restriction was to prevent private mental health facilities from receiving funding and to avoid a return to warehousing of mentally ill patients. Even with restrictions, the ACA can be perceived as beneficial for those with substance abuse and addiction problems to gain access to treatment. The coverage under the ACA may not lead to long-term outpatient treatment but can impact how services are provided.

In addition to the ACA, the Paul Wellstone-Pete Domenici Mental Health Parity and Addiction Act (MHPAEA) requires most insurance plans to provide the same level of benefits for mental health and substance abuse disorder services that they provide for other healthcare conditions (Schmidt & Tuohy, 2014). MHPAEA is effective for insurance plans years beginning on or after July 1, 2014. To ensure the ACA and MHPAEA are fairly and effectively implemented, the federal final rule clarified the scope of service eligibility as follows:

> (a) the six classifications of benefits (i.e., inpatient in and out-of-network, outpatient in and out-of-network, emergency care, and prescription drugs) were never intended to exclude intermediate levels of care (i.e., intensive outpatient, partial hospitalization, residential). Thus, expect these to be covered in insurance plans; (b) the language in the final rule on scope makes it clear that each classification and sub-classification has to meet all parity tests within each classification; and (c) although neither the Interim Final Rule (IFR) or final rule mandate specific services required to be offered by plans under the six classifications, the final rule clarifies that plans must assign intermediate services in the behavioral health area to the same classification as plans or issuers assigned intermediate levels of services for medical/surgical conditions. (Schmidt & Tuohy, 2014, pp. 19–21)

Legislatively, the ACA and MHPAEA have elevated the treatment for substance abuse and addictions to the level of other chronic illnesses. What remains to be seen is if they will have far-reaching positive outcomes on access and coverage of substance abuse treatment within the healthcare arena.

Considerations for Counselors Working in Rural Areas with Addiction Population

Various professionals (e.g., counselors, social workers, therapist, criminal justice personnel) work with and deliver services to persons with substance-related and addiction problems in different settings. At times these various professionals are required to come together to assist the substance abuser because his or her issues reach beyond the presenting problem of substance abuse. Often, counselors have to address co-occurring disorders in clients and may need to refer the client for specialized services. Knowledge of community resources is necessary if counselors are to be effective in their delivery of services. In addition to poverty, lower levels of education, limited career opportunities, long travel distances, lack of resources, and lack of diversity, alcoholism is identified as one of the aspects that make counselors' work and lifestyle challenging (Breen & Drew, 2012). The reminder of this section presents considerations for counselors working with substance abusers.

Resource barriers Just as with other human and social services in rural areas, disparity between needed and available services for SRAD can put counselors at a disadvantage as they identify, plan, and deliver service to clients. In addition to the barriers of long travel distances for rural residents to obtain services, low population densities, and limited supplies of specialized providers and services, counselors in rural areas encounter a host of work-related barriers as well. Personnel and administrators working in substance abuse treatment facilities cited low salaries, long hours, limited opportunities for training and continuing education, poor funding, heavy caseloads, insufficient time for one-on-one care, stigma associated with substance abuse, occupational burnout, and excessive bureaucratic demands as barriers to providing effective intervention (Appel, Ellison, Jansky, & Oldak, 2004; Gallon, Gabriel, & Knudsen, 2003; Knudsen, Ducharme, & Roman, 2006).

Pullen and Oser (2014) used focus groups of rural and urban counselors to examine barriers to providing effective substance abuse treatment. The results for both rural and urban yield the following themes: inadequate funding, transportation challenges, bureaucratic challenges, and lack of interagency cooperation, along with subthemes within both focus groups. The barrier of inadequate funding manifests in various ways for rural and urban counselors, in which both "emphasized that underfunding creates challenges for meeting basic client needs, as well as attracting and retaining qualified counselors" (p. 895). Rural and urban counselors also identified difficulty accessing and providing educational resources for counselors and clients because of budgetary constraints as a barrier. Both groups of counselors believed that having to pay out of pocket for continuing education, which benefits the institutions they work for and the clients they serve, is a major disincentive for counselors. Both rural and urban counselors agreed that providing educational materials to facilitate client recovery is important. Furthermore, both rural and urban counselors perceive that funding challenges may disproportionately affect rural area because rural areas have little to no options for multiple treatment facilities. Inadequate funding subthemes for rural counselors included a lack of treatment facilities (e.g., building resources) and substandard facilities. Beyond physical plant and treatment environment issues, rural counselors stressed that more adequate funding could address the basic concerns and improve outreach to clients. On the other hand, inadequate subthemes for urban counselors included difficulty in meeting the needs of non-English-speaking clients, lack of technological resources such as individualized computers, heavy caseloads, and understaffing. In a similar study, Edmond, Aletraris, and Roman (2015) found that a treatment quality differs between urban and rural centers in ways that are subject to resource availability (including personnel and other services) (see Research Box 28.1).

Research Box 28.1

Edmond et al. (2015).

Objective: To examine the differences in treatment quality in rural and urban centers and to determine if the differences in treatment quality are contextualized by centers' structural resources.

Method: Utilizing combined data from two representative samples of SUD treatment centers, a series of multivariate regressions were used to analyze the association between center rurality and various indicators of structural characteristics and treatment quality. Interaction effects were further examined between structural characteristics and treatment quality indicators.

Results: Structural and quality differences were found between rural and urban treatment centers. Rural centers had reduced access to highly educated counselors, were more likely to be nonprofit and dependent on public funding, offered fewer wraparound services, and had less diverse specialized treatment options. Also, rural centers were less likely to prescribe buprenorphine as part of their treatment but were more likely to employ nursing staff and offer specialized treatment for adolescents. Rural center access to physician contextualized the association between center rurality and the more limited provision of wraparound services.

Conclusion: Treatment quality differs between urban and rural centers in complex ways that are subject to resource availability.

Questions:

1. What are the primary structural and quality differences between rural and urban treatment centers?
2. Which type of medical personnel was associated with the level or wraparound services?
3. Why do you think rural centers were less likely to prescribe buprenorphine?

Not surprising, transportation was identified as a barrier more for rural counselors than urban. Getting to treatment facilities was a barrier for rural counselors not only because of a lack of transportation or having to rely of family and friends but also because of rising gas prices. Conversely, transportation was a problem for urban counselors because clients do not have the resources to get to treatment facilities or to fix their car. Rural and urban counselors perceived bureaucratic challenges as a barrier to delivering substance abuse treatment because of excessive paperwork, and the considerable time invested into navigating bureaucratic obstacles often delays client entry into treatment programs. As subthemes, rural counselors cited paperwork as a reason for feeling challenged for time and ultimately contributes to burnout. Urban counselors indicated that paperwork coupled with other extraneous non-counseling duties has altered the approach to managing clients. Delays in getting clients into treatment, especially in rural areas, can undermine successful outcomes. Moreover, when clients have appointments that are scheduled far in advance and when they have to wait hours once they arrive for an appointment, establishing effective rapport with clients is difficult, and these issues also delay client entry into treatment for rural residents. Counselors saw these issues being exacerbated for rural clients with comorbid conditions like mental health disorders (Pullen & Oser, 2014).

The last barrier to client success identified by rural and urban counselors in Pullen and Oser's (2014) study was the lack of interagency cooperation. Both groups of counselors considered effective treatment of substance abuse to also include a variety of other complimentary services (e.g., detox, mental health) that require communication among a network of facilities and providers. Although services can be arranged, the networks connecting clients to services need to be further developed. Counselors often experience frustration with having to arrange other services for their clients because their programs or facilities are nonmedical and are not equipped, for example, to make medical arrangements. For rural counselors that have to network with limited facilities that cover a large geographic area, client access is a challenge. Subthemes for both rural and urban counselors for lack of interagency cooperation including no continuum of care and lack of detoxification facilities and clients must improvise to access treatment services. In addition, rural counselors identified challenges in meeting housing, dental, and medical needs of clients as barriers (Pullen & Oser, 2014).

Dural relationships Among the many factors that influence the delivery of rural behavioral healthcare are overlapping or dual relationships (National Rural Health Association, 2008). The barrier that counselors and other service providers face in rural communities is that of familiarity (it is common for everyone to know everyone). The lack of anonymity can create problems with confidentiality or problems with respect for confidentiality by residents, resulting in some people foregoing treatment. Often, the occurrence or perception of the violation of confidentiality can deter substance abusers from seeking treatment. In many instances, it is the client who discloses that he or she is receiving services. For example, a client may approach a counselor in the grocery store and begin discussing his or her case. Although the counselor did nothing to lead to this disclosure, the client inadvertently revealed to anyone within earshot that he or she is a client of a specific agency who is receiving certain services. When the counselor or service provider also lives in the same rural areas in which he or she works, this can exacerbate the problem of rural substance abusers' resistance to prevention and treatment.

Cates, Gunderson, and Keim (2012), counselors working in frontier, small, and rural communities, noted that in conjunction with escalating recognition of rural service provisions has come an increasing consciousness of the unique ethical considerations to service delivery in rural communities. The unique considerations for counselors in RFT communities may be particularly challenging in relation to stigmatizing conditions such as substance abuse and addiction. According to Cates et al. (2012), the ethical dilemmas encountered by counselors in rural areas may be more difficult to resolve because of social and geographic isolation, limited resources, sparse population, and cultural expectations that distinguish those communities. Clearly, the context in which ethical conflict occurs can affect the way in which rural counselors apply ethical principles. Cates et al. (2012) suggest that rural counselors face the challenge of working with ethical codes that are designed basically for less interdependent urban areas (see Chap. 6 for additional information on ethical behavior and dual relationships). A similar problem may arise when the counselor does not understand the culture and local traditions and values of RFT communities, inadvertently pushing away those in need of services (Kraman, 2004). Breen and Drew (2012) in a study of the effects of rural context on the practice and experience of rural counselors found that counselors need to get to know the rural community in which they work and understand and respect their value; otherwise, counselors will not earn the trust of residents.

The geographic and social structure of rural communities creates multiple relationships. Rural counselors may gain access to confidential information when they are performing tasks in a capacity unrelated to their job functions. For example, a counselor who serves on the town's school board discovers during a meeting that a schoolteacher has missed many working days because of a significant alcohol problem. Conversely, in urban areas, the risk of such an occurrence is reduced greatly simply because of the availability of alternative clinicians and facilities (National Rural Health Association, 2008). The magnitude of the restrictiveness of RFT communities on the ability to separate personal and professional boundaries is illustrated by the types of professionals who are trained in mental healthcare and/or substance abuse and those who may not be trained but will likely be called upon to deal with clients requiring intervention (see Table 28.1).

Cross addiction Broadly defined, cross addiction is being addicted to two or more substances simultaneously. One issue that counselors may have to address in the rehabilitation of substance abusers in rural areas is the situation in which clients with an addiction are being treated with prescription medication for bona fide symptoms. For example, a client may be prescribed a stimulant (ADHD), benzodiazepines (anxiety), or opiates (pain) for treatment of a condition. These medications stimulate the part of the brain called the pleasure center (dopamine) that regulates pleasurable activities (in this case, addictive behavior). Thus, the substance abuser is given another addictive drug, which may lead to relapse. In addition, cross-addiction ("the ability of one classification of drug to produce a tolerance to the effects of another pharmacological classification") and potentiation ("the ability of the combined action of some drugs used together to be greater than the sum of the effects of each drug being used alone") are ususal outcomes (Stevens & Smith, 2013, p. 60). The other issue that is prevalent in rural areas is that patients often "doctor shop" (going from one doctor to another) to get various prescriptions. The outcome is that the doctors do not know that the other is prescribing medication to the patient. For persons with disabilities and chronic conditions, it is common for them to be prescribed multiple medications for short, immediate, or long term. The counselor should consider periodically completing a medication survey of the client.

Table 28.1 Behavioral health and the associated workforce in rural areas

Adolescent psychiatrist
Behavioral health aide
Case manager
Counselor
Emergency medical technician
Emergency room nurse
Emergency room physician
Marriage/family therapist
Primary care physician
Psychiatrist
Psychiatric nurse practitioner
Psychiatric physician assistant
Psychologist
Social worker
Substance abuse counselor

Adapted from the National Rural Health Association (2008)

Evidence-based practices In recent years, evidence-based practices (EBPs) have emerged in rehabilitation counseling and behavioral health as a benchmark of quality care. In rural areas, which are already underserved and underfunded, most behavioral health professionals do not have the time or training to plan and conduct clinical trials or to carry out pilot studies necessary for obtaining larger grants (US Department of Health and Human Services, 2011). Despite the growing emphasis on EBPs, there continue to be a gap between the types of substance abuse prevention and treatment activities that research has shown to be effective and those implemented in community settings (Saul, 2008). Furthermore, the limited resources and capacity of rural behavioral health providers restrict their ability to implement

EBPs or to develop new EBPs (Emshoff, 2008). However, rural providers have the advantages of having "developed programs specific to their areas, which may be quite successful in improving availability, accessibility, and acceptability of behavioral health services in rural areas" (US Department of Health and Human Services, 2011, p. 7). The suggestion is that rural providers are in a better position to understand the unique needs of their communities, to adapt programs and treatments, and to understand the culture of residents. In fact, the notion that rural providers that live in the community are more knowledgeable of its needs has been extended to suggest that inclusion of indigenous nonprofessionals is a catalyst for change in rural communities (Chakradhar, 2009, Harley, Savage, & Kaplan, 2005; Ungar, Manuel, Mealey, Thomas, & Campbell, 2004). The combining of formal and informal resources in a community to build community networks can enhance successful outcomes (Harley et al., 2005) (see the Chap. 37 for additional information on indigenous volunteers and paraprofessionals).

Counselor competency/self-efficacy Counselor knowledge, skills, and competency are considered key components to working effectively with any population. Counselors working in substance-related and addictive disorders in rural communities may find themselves one of the few professionals available to clients. Thus, counselors must have a high level of self-awareness and self-efficacy. In Breen and Drew's (2012) study on counselors in rural school and mental health settings, three subcategories describing self-efficacy emerged: confidence in providing a broad range of services, responsibility, and community contribution. Counselors in the study indicated that "counselor self-efficacy reflected the need for counselors to be mature and confident in their roles and be able to provide a broad range of services" because in a small town the counselor may have "to do it" because there is no one else or because you have multiple roles in an agency (p. 6). Responsibility referred to counselors doing due diligence (i.e., avoid doing harm) because often clients come to them not with but for answers. Even after the counseling relationships are terminated, clients still come to rural counselors because they are known, recognized, and visible; thus, the responsibility of rural counselors is ongoing with clients. Finally, "rural counselors not only provide services in their work setting but in the community" (Breen & Drew, 2012, p. 6). That is, they are serving a community need as a key component in the community, and people come to them for a variety of different things. Counselors are perceived as the expert (i.e., he or she knows what to do).

Approaches to Service Delivery

Treatment of substance abuse and addiction consists of a variety of approaches, therapies, and strategies. The intent of this section is not to prescribe which treatment methods counselors should use, rather, to discuss considerations for the treatment process with rural populations and to provide examples and resources to aid them in their deliberation. The reader is also reminded that treatment is an individualized approach that is designed to best meet the specific needs of the persons. That is, the approach will vary based on age, gender, cultural attributes, sexual orientation, and other pertinent variables. An individual may benefit from one or a combination of therapeutic approaches (e.g., individual counseling, group counseling, motivational interviewing, cognitive-behavioral therapy). Initially, the treatment process for all substance abusers should start with an assessment and diagnosis and conclude with relapse prevention and recovery. Oser et al. (2011) examined rural drug users' substance use histories and retrospective substance abuse treatment service utilization patterns and found that selected predisposing, historical health, and enabling factors were significantly associated with the utilization of substance abuse treatment among rural drug users. Moreover, one consideration that counselors should be aware of is that despite the high levels of recent and lifetime substance use among rural drug users, treatment services are underutilized.

Telehealth The use of telehealth (the use of information technologies and telecommunication systems) to make health education and healthcare available despite distance or travel barriers is being used in various aspects of healthcare delivery and mental health counseling. Two of the main benefits of telehealth are being able to connect the patient with a specialist at a remote site instead of asking him or her to travel to another county or community to obtain care and quality care at low costs. Because substance abusers in rural areas overwhelmingly receive outpatient services, telehealth may provide promise for addiction treatment. Petiwala et al. (2014) indicate that telehealth can be used in a variety of ways within the substance abuse treatment field: web-based educational programs, video conferencing techniques, and at-home devices (see Table 28.2 for the description of telehealth options in providing substance-related and addictive disorder services to rural areas). To emphasize not only the benefit but also the need for telehealth, the National Telemedicine Foundation (2014) likened access to care in rural parts of the United States to that of third world countries. In addition, telehealth allows for ongoing training of service providers. However, administrative, infrastructure, funding, and limited rural broadband remain as barriers in many rural areas. (See Chap. 4 for more information on technology.)

Table 28.2 Telehealth options for providing substance-related disorder services to rural areas

Therapeutic Education System (TES) – is an interactive computer-delivered, web-based, psychosocial skills training built upon the validated community reinforcement approach to behavior change. Used to teach basic cognitive-behavioral skills and improve psychosocial functions
Video conferencing – is used to provide specialized care/counseling through video feed from an on-site service provider. Service providers can exchange information on clients to provide a multidisciplinary approach for the client's benefit
In-home messaging device (IHMD) – is a small, beeper-like device that is used to assess client condition using text messaging and questions of substance use while also providing self-management education. IHMD is focused on early recovery steps (i.e., motivation, commitment to abstinence, early relapse prevention, recovery supports)
Interactive voice response (IVR) – is used in clients' homes through their landline telephones by calling a toll-free number from their phones to record their responses to questions about their substance use that day or week. Self- management education models can also be provided through the system

Adapted from Petiwala et al. (2014)

Counseling approaches Counseling for substance abusers depends on a number of factors and individual need; however, certain counseling approaches demonstrate effectiveness with substance-related and addictive disorders. In this section, several of those counseling approaches are presented. One of the more widely used evidence-based counseling approaches in substance abuse counseling is cognitive-behavioral approach (Ellis, 1994). Leukefeld, Godlaski, Clark, Brown, and Hays (2015) present a model, Structured Behavioral Outpatient Rural Therapy (SBORT), that was developed especially for rural clients entering substance abuse treatment. The approach is designed to continually communicate and teach an "A-B-C" cognitive-behavioral approach to problem solving and change (see Discussion Box 28.1). SBORT combines individual and group methods, using structured storytelling rather than traditional role-playing. Motivational interviewing (Prochaska & DiClemente, 1982) is the approach used throughout SBORT to engage clients in a process of change (Leukefeld et al., 2015). Other components of SBORT include case management, social skills training, behavioral contracting, and

Discussion Box 28.1: Substance Abuse Treatment in Kentucky Targets Rural Residents

Researchers at the Center on Drug and Alcohol Research at the University of Kentucky have developed behavioral therapy designed for application in rural areas. This focuses especially on rural substance abusers. The model, Structured Behavioral Outpatient Rural Therapy (SBORT), was developed and applied in Eastern Kentucky and specifically identifies and assists clients/patients in overcoming rural-specific barriers to substance abuse and addiction treatment. The model combines behavioral contracting with case management, allowing rural clients to better able to complete treatment and utilize resources in their community.

For additional information, see the following resources:

Leukefeld et al. (2015)

Questions:

1. What are the advantages/disadvantages of this model?
2. Can this model be applied to all ages?
3. What issues must be considered to apply this model?

thought mapping. Table 28.3 provides a description of the 12 skills sessions.

At the core of motivational interviewing (MI) is a relationship-centered, client-centered system of change. The emphasis is on client self-responsibility and promotes an invitational style for working cooperatively with clients to generate alternative solutions to behavior problems. The counselor uses various techniques and interpersonal skills (e.g., asking open-ended questions, reflective listening, affirmation, summarization, and eliciting change talk) known to be effective agents of change. In addition, clients are viewed as allies who play a major role in their present and future success. The belief is that clients have positive attributes, and the underlying assumption is that clients desire positive change (Corey, 2013). There are four counseling principles of MI. The first is *expressing empathy* in which the counselor communicates to a client with his or her understanding of the client's point of view, feelings, experiences, and behaviors. The objective is to normalize ambivalence and to demonstrate the counselor unconditionally accepts the client. The second principle is *developing discrepancy*, which is directive in nature

Table 28.3 SBORT 12 skills sessions

Session 1: Managing thoughts and fantasies about alcohol and drugs – to discuss and identify thoughts and fantasies about AOD use and feelings they can evoke. This session helps to explore how thoughts and fantasies might lead to relapse so that each client can develop beliefs and skills to manage them productively
Session 2: Coping with cravings and urges – to help the client recognize triggers, monitor triggers to deal with them, and find a way to cope with cravings
Session 3: Relaxation – to help clients to begin to discover and cultivate in themselves the ability to relax or at least prevent the acceleration of distress, even in difficult situations
Session 4: Increasing pleasant activities – to gain control over negative feelings as a means to avoid returning to AOD abuse
Session 5: Problem solving – to help client understand a situation only becomes a problem when there is no solution. Help clients to recognize a problem, identify the problem, consider various approaches, and select the most promising approach
Session 6: Awareness and management of negative thinking – to help clients understand the way we think influences how we feel. Replace negative thinking with more helpful thinking to empower persons to actively and productively address the challenges they face
Session 7: Anger awareness and management – to recognize that anger is neither good nor bad but is an intense feeling and depending on our reaction to it can be either constructive or destructive
Session 8: Interpersonal violence – to understand and apply the eq. P x S = V, where violence (V) is the product of a particular person (P) who responds in a particular situation (S). Identify and practice social skills that are viable alternatives to violence
Session 9: Close and intimate relationships – review some basic communication skills, focusing on intimate relationships. Stress skills in giving and receiving criticisms and compliments
Session 10: HIV/AIDS – to acquaint clients with understanding HIV and presenting strategies they can use to protect themselves and others from the virus. Knowing that HIV risk is associated with the consequences and relaxing effects of AOD use
Session 11: Enhancing social support networks – recognizing what kind of help you need and accessing the help you need and learning how to approach others and ask for help. Help may come from family and nonfamily members
Session 12: Self-help and connectedness – helping clients understand the basic tenets and approaches of self-help groups

Adapted from Leukefeld et al. (2015)

and requires active listening and reflecting from the counselor. When the client experiences a discrepancy between his or her beliefs and behaviors (cognitive dissonance), the client will seek to reduce that inconsistency. The third principle is *rolling with resistance*, in which resistance is not a point to argue but is viewed as a signal that the session should go in a different direction. The final principle is to support self-efficacy, which promotes client autonomy, and the counselor's belief in the client's ability to change will increase self-efficacy (Aasheim, 2016).

Brief therapy is used to treat disorders within a preestablished time limit (Corey, 2013). The application of brief therapy can range from a 5-min explanation of the harm of alcohol and other drugs (AOD) by a health provider to a mental health counselor encouraging a client to see if he or she can stop drinking or taking drugs on his or her own and to more structured programs. The goal is for the client to reduce the risk of harm from AOD. The stages-of-change model and techniques of motivational interviewing are the basis of intervention techniques. The type of intervention is generally related to the level of AOD use (Fisher & Harrison, 2013).

A host of other treatment interventions and approaches are available to those with substance abuse and addiction disorders including but not limited to psychotherapeutic approaches, treatments based on the medical model of disease, group and family counseling, pharmacological procedures, and aversive conditioning (not widely used). However, these clients would typically be seen in a treatment setting. The setting in which a person received treatment may also vary depending on the users' frequency and level of use and the drug or substance used.

Self-help groups Mutual-help groups play an important role in substance abuse treatment. Virtually all substance abuse treatment services incorporate self-help groups (Leukefeld et al., 2015). Kelly and Yeterian (2011) suggest that self-help groups emerged and proliferated in part, because professional resources have struggled to keep the problems of substance abuse in check by themselves. The oldest and most widespread self-help group in the United States is Alcoholics Anonymous (AA), and because of its longevity, size, and influence, the vast majority of self-help research has focused on AA. Although a body of literature supports the effectiveness of self-help groups (e.g., Kelly, Stout, Zywiak, & Schneider, 2006; McKellar, Stewart, & Humphreys, 2003; Moos & Moos, 2006), questions have arisen about their suitability for certain populations (such as dual diagnoses, women, ethnic minorities). In rural communities, self-help groups may be difficult to find because of location, problems with transportation, and concerns about confidentiality and anonymity. On the other hand, self-help groups may reduce the need for more costly professional treatment services. Yet, self-help groups are facilitated by peers, not professionals, which may call into question the skill set of group members to help others with addiction disorders. Perhaps a modification in the organizational structure of self-help groups to reflect more of a paraprofessional approach may address some of the concern of skills and competency.

Strategies to Address Substance Abuse in Rural Areas

Substance abuse in rural areas requires a comprehensive approach that considers the unique and interrelated challenges of rural communities because it affects rural communities in multiple ways. According to Gale (2016), individuals with substance abuse disorders are impacted by the direct cost, which includes ongoing health problems, overdose deaths, greater risk of homelessness, exposure to human immunodeficiency virus (HIV) and hepatitis C (HCV), and incarceration. The other levels involve the social problems affecting the community (e.g., domestic violence, criminal behavior to support drug habits, child neglect, prostitution, disintegration of social networks). Beyond the challenges previously mentioned for coping with substance abuse in rural communities, rural communities must also curtail excessive prescribing practices by physicians, implement harm reduction programs (e.g., naloxone and needle exchange), and hire paramedic level emergency medical service (EMS) system personnel. In response to the drug crisis in rural communities, Gale (2016) developed policy recommendations (see Table 28.4). In addition to the recommendations in Table 28.4, several specific strategies to assist communities facing a drug epidemic are discussed in this section. These strategies are just a few examples for consideration and not an exhaustive list.

Drug court Drug court is not a new strategy. Drug courts were created in 1989 as an alternative to pronouncing unenforceable sentences of incarceration and with the goal of sending defendants to effective addiction treatment (Roper & Owens, 2006). Drug court is a judicially supervised court docket that adjudicates cases involving nonviolent substance-abusing offenders under the juvenile, adult, and family tribal justice system (Huddleston, Marlowe, and Casebolt, 2008). The offender (client) must comply with the requirements (i.e., weekly attendance in drug court, compliance with treatment, random drug testing). Drug court brings to bear added accountability to the drug offender. If the offender fails to comply with any of the conditions imposed by the judge, the judge then imposes additional sanctions. Drug court offers the advantage of providing the offender with “repetitive reinforcement of target behaviors and requirements, which are especially important because of the cognitive impairments that occur in this population” (Huddleston, 2005, p. 3). In addition, the ongoing contact of drug court with the client, which reinforces treatment attendance and participation, increases the probability of the client completing long-term treatment. Drug court service providers adjust treatment services to address the specific conditions and needs of the drug user. Also, the court establishes support structures (e.g., self-help groups, sponsors) and, in conjunction with the client, plans ways to identify and manage his or her triggers and cues to relapse (Huddleston, 2005).

Faith-based and community reentry services Faith-based organizations are the initial point of contact for rural adults and families experiencing problems. In addition, these organi-

Table 28.4 Strategies for substance abuse in rural areas

Support the implementation of models to engage rural communities in addressing drug issues – develop broad-based community coalitions, develop community-level substance and pain management services, implement harm reduction and prevention strategies, and engage law enforcement. Next, address economic issues that encourage vulnerable populations to sell their prescriptions for financial gain. Finally, monitor and evaluate rural programs focused on prevention and treatment
Disseminate evidence-based prevention programs tailored to the needs of rural communities – provide information focused on community education for adolescents and adults, stigma reduction, harm reduction, and diversion control (e.g., safe storage and disposal programs). Provide technical assistance and funding to support implementation. Finally, engage key stakeholders. Identify appropriate websites
Increase the implementation of harm reduction strategies – use educational efforts to increase the acceptance of harm reduction strategies by state- and community-level policymakers. Reduce legal and regulatory barriers for the development of harm reduction programs and increase funding, as well as locate program in convenient locations to ensure access. Finally, increase access to naloxone by changing state laws to expand use by first responders and provide training to support naloxone use and modify pharmacy and prescribing regulations to increase access to naloxone
Expand access to substance use treatment services including medication and assisted treatment and traditional psychosocial substance use treatment programs – develop an appropriate and sustainable continuum of outpatient and inpatient care including medication-assisted treatment, psychosocial treatment programs, mental health services, and integrated primary, substance use, and mental health services. Encourage primary care providers to implement buprenorphine use in their practices. Collaborate with key partners at the national and state levels to expand buprenorphine. Work with legislative and policymakers to create innovative use of and payment for underutilized critical access hospital facilities. Develop transportation programs. Encourage treatment programs to accept Medicaid as a payment source
Enhance the capacity of rural EMS systems to respond to drug overdoses and reduce the rate of overdose deaths
Expand the substance use workforce in rural communities – develop mentoring programs, recruit rural students interested in pursuing careers as counselors, develop state and local loan repayment and scholarship programs, expose primary care professionals to substance use and drug treatment training, and extend eligibility for loan repayment and to licensed and/or certified counselors

(continued)

Table 28.4 (continued)

Promote the use of evidence-based prescribing guidelines developed by appropriate professional organizations
Strengthen state prescription drug monitoring programs and greatly strengthen sharing of prescription information across state lines
Support increased public health engagement in addressing drug and related HIV and HCV issues
Support availability of recovery and peer support services
Expand the use of substance use treatment as an alternative to incarceration for drug users

Adapted from Gale (2016), Goodwin and Tobler (2013)

zations have the knowledge and experience in providing assistance to those in need (Hartman, Barber, Arndt, & Wassink, 2006). Hartman et al. assessed the services and support provided by faith-based organizations having the unique mission to serve those in need. The authors found that faith-based organizations provide both a wide variety of direct practical services and the opportunity to establish a sense of community belonging. The recommendation was that both corrections and substance abuse treatment representatives from faith-based communities might benefit from training concerning reentry clients. The value of faith-based organizations in rural communities increases in light of state budget cuts because many human services in rural areas and small towns are eliminated. A concern remains in rural areas in using faith-based organizations for substance abusers – shame and judgmental attitudes. Thus, faith-based organizations will need to be welcoming of such a vulnerable population and knowledgeable of the obstacles faced by individuals in recovery. The answer to success for individuals in recovery is sustainability of community support. Thus, to ensure long-term support, the service provision for support must come to the neighborhood and not the reverse. Research suggests that community interventions that draw on existing resources and assets of rural populations will have a higher rate of success, and using community attributes to develop rural-specific programs of intervention, prevention, and treatment will generate the most effective strategies (Carsey Institute, 2006; Office of Justice Programs, 2000; Regional Prevention Services, 2013).

Prevention Too often, substance abuse prevention is seen as separate from intervention when in essence prevention and treatment is a continuum of care for substance abusers. This continuum of care is made up of all activities that reduce substance use disorders in a community: prevention, treatment, and continued maintenance (The Health Foundation of Greater Cincinnati, 2010). The focus should be on both, simultaneously. Prevention occurs through education, outreach, wraparound services, and better screening at intake and during psychosocial screening. Prevention strategies should be appropriate for age, gender, and culturally diverse populations. In rural areas, prevention should be a partnership effort consisting of service providers that address an individual's psychosocial, medical, vocational, and cultural concerns. To better address substance abuse in rural areas, service providers should look to include entities beyond the traditional health and social service providers and consider Cooperative Extension Services in rural areas. Bachtel (1984) outlined steps in a prevention program and suggested educational inputs from Cooperative Extension. He suggested that an increased knowledge of local patterns of drug can help mobilize citizen groups to develop prevention programs tailored to local conditions. Bachtel's recommendations included: (a) have community-wide organization, (b) know the community, (c) use reliable sources, (d) have a plan, (e) define responsibilities, and (f) work with community leaders. More recently, Shaklee, Bigbee, and Wall (2012) suggested that Cooperative Extension professionals are viewed as trusted professionals in rural communities who can bring critical skills to human service teams, and multidisciplinary prevention programs offer particularly good contexts for county extension personnel to collaborate.

Summary

In rural areas, counselors need to connect the dots when working with rural substance abusers and address not only the substance abuse but also other relevant and impactful factors of poverty, unemployment, mental health issues, other disabilities, and so forth. That is, the decision to go into treatment is influenced by multiple variables including but not limited to voluntary or involuntary (court ordered) admission, poverty, affordability, availability within their community, and family. In fact, counselors should be aware that the family members of rural clients are contributing factors to their substance use, as well as subverting efforts to recover (Pullen & Oser, 2014). An understanding of rural culture and community norms is essential for counselors working in rural communities.

Treatment and recovery for substance-related and addictive disorders is a process in which the client can have stages of success and regression. For clients in rural, frontier, and territory areas the barriers to substance abuse treatment are real and formable. The solutions that are needed to address rural addiction are related to availability and accessibility of treatment facilities, costs of treatment, interrelated social and economic disparities, cultural and attitudinal barriers about help from outsiders, and appropriate and sustained funding for treatment programs. The current prevalence of substance-related and addictive disorders in rural communities provides both a baseline of the severity of the problem and prediction of future outcomes if a more proactive stance is not taken to address the problem. Overwhelmingly, the literature concurs that addressing substance abuse in rural areas requires input from professional and community constituents alike.

Resources

Addiction Counseling Competencies: www.store.samhsa.gov/shin/content/SMA12-4171/SMA12-4171.pdf

Association for Addiction Professionals Code of Ethics: www.naadac.org/code-of-ethics

Behavioral Health Center for Rural Health: www.ruralhealth.und.edu

National Rehabilitation Information Center (Substance Abuse & Individuals with Disabilities: www.naric.com/?q=en/publications/volume-6-number-1-january-2011-substance-abuse-individuals-disabilities

National Rural Institute on Alcohol and Drug Abuse: www.uwstout.edu/profed/nri

Rural Mental Health: www.narmh.org

Rural Mental Health and Substance Abuse Toolkit: www.ruralhealthinfo.org/commujity-health/mental-health

Substance Abuse and Mental Health Services Administration (SAMHSA): www.samhsa.gov

U.S. Department of Health and Human Services – *Bringing Excellence to Substance Abuse Services in Rural and Frontier America (Tap 20).* (2013, June 18).

Learning Activities
Self-Check Questions

1. What are the universal challenges in rural, frontier, and territory communities for clients seeking treatment?
2. What are the links between substance abuse, domestic violence, and intimate partner violence in rural, frontier, and territory communities?
3. What are the dimensions of multidimensional assessment as defined by the American Society of Addiction Medicine?

Experiential Exercises

1. Interview a counselor, social worker, or human service provider that works with clients with substance abuse problems, mental health disorders, or dual diagnoses in a rural, frontier, or territory community to determine their experiences and perceptions related to barriers/challenges and recommendations for service delivery.

2. Identify a rural, frontier, or territory community and develop a resource manual of services for clients with substance abuse and addictive disorders. Be sure to include all contact information, services offered, forms of payment, populations served, and other relevant information.
3. Attend a self-help group in a rural, frontier, or territory community. Write a paper about your experience.

Multiple Choice Questions

1. Which of the following contributes to substance abuse and addiction in rural, frontier, and territory communities?
    (a) Isolation
    (b) Poverty
    (c) Unemployment
    (d) All of the above
2. Which of the following best describes the effects of drugs on the brain and body?
    (a) Temporary or permanent
    (b) Situational or temporary
    (c) Long term or correlated
    (d) Connected or separate
3. Which of the following distinguishes rural substance abusers that enter treatment from their urban counterparts?
    (a) Rural admissions were overwhelmingly female
    (b) Rural admissions were older and less racially diverse
    (c) Rural admissions were more often refereed by the criminal justice system
    (d) Rural admissions were less likely to have a high school education
4. Which of the following are substance abusers in isolated rural areas likely to be referred?
    (a) Counseling and intensive treatment
    (b) Inpatient and self-help groups
    (c) Detoxification and counseling
    (d) Counseling and self-help groups
5. Which of the following is when law enforcement uncovers the presence of substance abuse problems in rural areas?
    (a) Responding to a disturbance of the peace call
    (b) Responding to a domestic violence or intimate call partner violence situation
    (c) Responding to a firearm discharge call
    (d) Responding to an animal neglect and abuse call
6. Which of the following best explains the higher rates of nonmedical prescription drug use among adolescents?
    (a) Their easy access to prescription drugs
    (b) Their lower perceptions of harm
    (c) Their desire to be accepted by peers
    (d) Their increased situation as latchkey kids
7. As an area becomes more rural, which of the following will the substance abuse treatment facility offer?
    (a) More specialized services
    (b) More residential services
    (c) Less specialized services
    (d) Less outpatient services
8. Which of the following is a barrier for counseling to establishing rapport with clients in rural areas?
    (a) Long wait time
    (b) Interagency cooperation
    (c) Dense populations
    (d) 90-day closure requirement
9. Which of the following may create dual relationships for counselors that work in rural communities?
    (a) Geographic and social structure
    (b) Lack of knowledge of the culture and local traditions
    (c) Availability of alternative clinicians
    (d) Too many facilities
10. Which of the following is a benefit of telehealth in rural areas?
    (a) Quality care at low costs
    (b) Reduced travel time
    (c) All of the above
    (d) None of the above

Key

1. D
2. A
3. C

4. D
5. B
6. B
7. C
8. A
9. A
10. D

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Marketing Vocational Rehabilitation Services in Rural Communities

29

Noel A. Ysasi, Lebogang Tiro, Matthew E. Sprong, and Byung Jin Kim

Overview

As discussed throughout each chapter, the demographic composition (i.e., lack of available job opportunities, less formal education, and poverty) in addition to geographical distance of rural areas from surrounding communities, can directly affect quality of life among people with disabilities (PWDs). Additionally, when individuals have to travel great distances for employment, personal stress can be placed on the job seeker and/or employee when there is a need to be close to home (e.g., caring for an elderly family member), ultimately affecting job stability and limiting employment options. On the contrary however, when a job seeker is able to commute, they may be oblivious to current employment opportunities within their surrounding area. Oftentimes, this occurs when small businesses within rural communities market their services, but generally do not post available job openings. For a person with a disability who is solely relying on Internet browsers to search for work, they may continue to stay unemployed despite only being 10 miles away from a prospective job opportunity.

To counter the aforementioned issues, marketing can be an essential tool; however, it must be able to reach its intended audience and, in this case, residents of rural communities. *When thinking of marketing, what comes to mind? Websites? A telemarketer?* Although these are two commonly used marketing strategies and techniques, they may not be the most practical method for promoting a product. For instance, not all rural residents have Internet capability (despite our technological improvements in American society), and most would agree that staying on the phone long enough to listen to a telemarketer's "sales pitch" is undesirable. *So how does one advertise their services? How does a vocational rehabilitation counselor (VRC) reach consumers and employers, while keeping the person "on the phone" long enough to explain the product being sold?* Based on the abovementioned challenges, the following marketing recommendations and approaches are discussed to enhance VR service delivery in rural communities for PWDs and employers: (a) outreach and brand marketing, (b)

N.A. Ysasi (✉)
College of Health and Human Services, Rehabilitation Services and Rehabilitation Counseling, Northern Illinois University, DeKalb, IL, USA
e-mail: nysasi@niu.edu

L. Tiro
University of Kentucky, EDSRC Department, Lexington, KY, USA
e-mail: lti223@g.uky.edu

M.E. Sprong
Rehabilitation Services and Rehabilitation Counseling, School of Allied Health & Communicative Disorders, Northern Illinois University, Dekalb, IL, USA
e-mail: msprong1@niu.edu

B.J. Kim
University of Kentucky, Lexington, KY, USA
e-mail: bki256@g.uky.edu

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internal marketing, (c) content marketing, and (d) effective approaches to providing outreach to employers and consumers.

Learning Objectives

Upon completion of this chapter, the reader will be able to:

1. Have an understanding of the challenges experienced by vocational rehabilitation counselors who provide services in rural communities
2. Be able to recognize the general needs and concerns among employers to enhance service delivery
3. Be able to identify marketing goals and strategies best suited for rehabilitation counselors and their agencies

Introduction

Vocational rehabilitation (VR) in America has traditionally experienced challenges toward successful service delivery, yet the demand for enhanced performance outcomes has never been greater, particularly for those who provide and receive services in rural communities. Specifically, the estimates of people with disabilities (PWDs) residing in rural America are reported at nearly 9 million (U.S. Census, 2015). Since the beginning of the rehabilitation counseling era, the emphasis has always been to improve the quality of lives for PWDs. This often entails a vocational rehabilitation counselor (VRC) with identifying employment objectives and needs for both the job seeker and employer, resume development, job placement, providing and teaching self-advocacy, job retention skills, and so forth. And though services for PWDs have improved as a result of various legislative movements (i.e., Americans with Disabilities Act), this population is generally underserved and even more so, when they reside in rural communities. According to Temkin (1996), the challenges faced by PWDs living in rural areas include limited resources, isolation, increased poverty, and decreased educational and employment opportunities. When job openings do occur, they are often categorized as "unskilled" which require limited to no education, leaving rural residents who receive a post-secondary education often relocate to expand their employment options. With the Workforce Innovation and Opportunity Act (WIOA) of 2014, states are accountable for meeting successful employment outcomes, while confronted with a strict budget for each fiscal year (WIOA, 2014). Subsequently, outreach and marketing VR services in rural communities can be problematic when personnel and resources are limited. For example, vocational rehabilitation counselors (VRCs) are often given excessive caseloads encompassing multiple surrounding counties and/or cities which prevent evenly distributed time for their consumers. Thus, the VRC must customize service delivery to increase performance outcomes through enhanced and innovative marketing strategies while investigating the needs of their consumers (Richardson & Gosnay, 2010).

Marketing can be defined as the ability to advertise a product by which the intended audience becomes attracted to purchase what is being offered. In the case of VRCs, the product in which they are marketing is job placement. But what differentiates a rehabilitation counselor from any other professional providing job placement services? Individuals with a degree in rehabilitation counseling are specifically trained in mental health counseling to understand the complexity of various medical conditions and disabilities, job placement, and forensic rehabilitation (i.e., life care planning). Unfortunately, many employers are often unaware of what VRCs provide, and thus, PWDs, and in particular individuals with a visible disability, can be at a disadvantage when seeking employment as a result of stigma and discrimination.

Thus, marketing VR services has always been a necessary driving force behind successful rehabilitation counseling services. This generally entails developing community partnerships with employers and PWDs which consists of educating individuals unfamiliar with your "product," about the specific services you provide. Most often, employers are interested in what you are selling, if it improves their business (i.e., generates increased revenue), while PWDs may be in search of a professional specifically trained to assist them with their employment goals. Nevertheless, employers and PWDs are oftentimes unaware of the various services VRCs provide and even more so, for those who reside in rural communities. With this in mind, we explore how vocational rehabilitation agencies and their counselors can provide effective marketing to enhance service delivery. We examine outreach and brand marketing and internal and content marketing and discuss effective marketing strategies when connecting with employers and job seekers.

Outreach and Brand Marketing Plan

Outreach and brand marketing are two key elements toward successful outcomes when VR agencies are establishing a plan to develop and/or improve its current marketing infrastructure. Unfortunately, many state government agencies are being reorganized or merged as a result of decreased state funding or recent legislative changes. Despite the aforementioned conversions, no agency should decrease outreach efforts nor should it affect how an agency identifies itself – "brand marketing" (U.S. Department of Health and Human Services [HHS], 2014). The primary goal of outreach involves VRCs connecting with prospective consumers to raise awareness of the services being provided. When working with employers, the rehabilitation counselor publicizes the available individuals that meet the requisite skills for current employment opportunities being advertised (HHS, 2014). The methods through which this generally occurs consist of email, phone calls, and direct contact/communication via in-person meeting, with the latter being the most effective. In a study conducted by Geo (2012), two outreach models were identified as the primary method for which services were marketed (basic and expanded business outreach). Basic business outreach consists of making initial contact either through presenting at or attending local community events. A common expectation among agency directors of their counselors involved at least 1 day in the field making direct contact with employers followed by 1 day of matching clients with available jobs in the community. Unfortunately, the basic outreach model did not extend beyond client placement although counselors frequently returned to employers for future job prospects while failing to offer additional services to the employer which are provided through the expanded model.

The marketing outreach model encompasses the same components of the basic plan, but includes VRCs disseminating information with regard to the general services provided, Americans with Disabilities Act, tax incentives, follow-up services, and job retention. When employers are unfamiliar with VR services and they take a "leap of faith" by hiring a person with a disability, trust can dissipate if the outcome is unsuccessful. Thus, the rehabilitation counselor follows up with employers despite job placement outcomes to ensure the development and/or continuation of a working alliance. This model aids toward safeguarding against common challenges experienced when an unsuccessful case closure occurs (i.e., less than 90 days) as not all clients are a "perfect fit" for the employer and vice versa. Also, when VRCs work toward establishing long-term working relationships extending beyond job placement, the result often leads to stronger partnerships between counselor and employer regardless of placement outcome (Geo, 2012).

Brand Marketing

When VRCs begin initiating outreach to prospective consumers, how others view the product in which you are selling is critical for success. Brand marketing is specifically designed to add value to the performance of an organization by having a clear internal perspective of what the brand is and how the external market views the product (Aaker, 1996; Dowling & Otubanjo, 2011; Keller, 2001; Urde, Baumgarth, & Merrilees, 2013; Vallaster & von Wallpach, 2013). Additionally, for the brand to be successful, a clear identity shared by all stakeholders is necessary (Dean, Arroyo-Gamez, Punjaisri, & Pich, 2016). In the case of vocational rehabilitation, brand marketing is identified based on how employers interpret what a VR agency is (based on their name and/or symbol; Aaker, 1996) and how it provides increased revenue for the business industry. *So how do you determine what your brand is and how do you get businesses to buy into the product?* A brand can be established and determined in a variety of ways such as business cards, email signatures, flyers, etc., which should be taken with careful consideration when developing your marketing plan. For instance, each of the aforementioned marketing tools could ultimately affect the outcome of job placement prior to establishing rapport or making direct face-to-face contact. A such example would be email signatures with a "handicap" logo. This can deter employers from replying as a result of the stigma commonly associated toward hiring PWDs (i.e., costs for accommodations are generally high, and PWDs often request time-off for "sick days"). Similarly, business cards with "vocational rehabilitation counselor" rather than "job placement specialist" may relay a similar message. However, the recommendation is not for a VR agency or rehabilitation counselor to change their name or title, but rather begin the working alliance without negative perceptions or preconceived notions of what your services entail. Case in point, a study conducted by Geo (2012) found rural agencies commonly marketed their VR program as a job placement organization rather than a disability serving program. The "brand" of each organization varies based on the services they offer, and thus, marketing should be tailored based on their needs and identity. Nonetheless, there are universal and necessary components of which should generally be applied by agencies and VRCs when marketing their services. Anderson (2012) reports the following 17 indicators for successful marketing programs:

1. Identify a primary account representative from rehabilitation to each company with whom the entity is working.
2. Spend more time discussing candidates for jobs currently open rather than "all" candidates for employment.
3. Make extensive accommodations the exception rather than the rule, especially with a new employer account.
4. Tour the company and share information gleaned from such a tour.
5. Learn the culture of the company.
6. Do not underestimate the importance of human resources if the business has such an office.
7. Place a high priority on professional marketing materials, not necessarily lengthy or expensive.
8. Professionally train your personnel in sales and marketing skills.
9. Recognize that every contact with a company is marketing and reflects upon the relationship.
10. Become an entity the employer can rely on.
11. Make every contact with the recruiter count.
12. Understand that approaching employers also means receiving them.
13. Avoid gimmick marketing.
14. Get involved in networking opportunities.
15. Evaluate the corporate connections you have in your community.
16. Match the level of the marketer to the level of the person with whom you are meeting.
17. Market to each company individually, with a customized message.

Internal Marketing

Aside from the abovementioned strategies for connecting with local communities and creating a "brand," an agency should consider the use of internal marketing (IM) to improve overall performance outcomes. Originally, IM was intended to assist members of an organization to be customer driven so that employees can meet the needs of its consumers (Saad, Hassan, & Shya, 2015). In addition to a customer-driven philosophy, IM is intended to create a positive working environment within its organization. Particularly, this is established by promoting a strong work commitment among its employees by safeguarding for work satisfaction and through various inspirational and motivational techniques (Chang & Chen, 2008). And though some similarities exist between brand marketing and internal marketing, the latter is specifically designed to ensure all vested parties within an organization are working in harmony (Peltier & Scovotti, 2005). Its premise is that all employees within an organization have a positive effect on the external relationships. For this to occur, coordination and cooperation must take place from *all* individuals employed within the agency, for instance, receptionists, vocational rehabilitation counselors, transition specialists, job placement specialists, and branch managers.

Moreover, Dean et al. (2016) described IM as an interaction between an organization and its stakeholders. However, this not only includes businesses, but consumers as well (e.g., PWDs residing in rural communities). In that regard, IM places a strong emphasis on employees understanding the critical role they play in consumer satisfaction by assisting them toward self-evaluation and self-improvement. When IM is implemented, the outcome is remarkably favorable for individuals on the receiving end. In a study conducted by Fortenberry and McGoldrick (2016), consumer satisfaction in health care facilities was found to be remarkably favorable when the agency implemented the use of IM. Although this would generally be apparent, not all agencies operate under this premise and, oftentimes, find themselves struggling toward marketing a product that is "attractive" to the intended population.

A method by which IM is established and marketed is through the development of a mission and vision statement, while setting goals directly related to the community for which they will be serving. When developing these statements, the organization should consider the culture of the rural community they are targeting. For example, if a rural town values family and collectiveness, it may be useful for the organization to emphasize this in the marketing plan. However, the organization should stay within their scope of practice and the services they can provide. If an organization is unable to provide a specific service due to general barriers discussed throughout the text, then VRCs should not market it. Once an organization is able to eliminate these barriers, a clear marketing plan can be established that is directly tailored to the community they will be serving.

Content Marketing

Throughout this chapter, we have discussed various recommendations for improved marketing strategies, but one question remains: *how does a State VR agency market their services while connecting with rural communities?* Content marketing can be described as the ability to distribute educational and/or promotional material to captivate and retain customers of the product being sold (Chaffey & Smith, 2013). Baltes (2015) adds to the term of content marketing as a way to assist consumers in understanding the types of services offered. Contrary however, Jarvinen and Taiminen (2016) state the content being marketed should be designed to solve clients' problems instead of promoting a company product. In the field of rehabilitation counseling nevertheless, the aim should be to demonstrate an agency's ability to equip clients with requisite skills to assist them in gaining employment, while tailoring services provided to their education and work history. The following recommendations consist of content marketing strategies for the VRC providing services to rural communities.

A vital component for successful marketing involves developing strategies to distribute your promotional materials precipitously following initial contact (i.e., to address questions relayed during the meeting) or when first becoming employed within the VR agency (i.e., to let employers know about who you are and the services you provide). Also, sharing "real-time" information to employers about available job candidates from an electronic applicant pool has proven to be quite successful (Anderson, 2001). The latter proves to be an effective method for the VRC when providing services to employers in rural communities. Specifically, once initial contact is made and rapport has been established, rehabilitation counseling professionals can begin sharing this "real-time" information particularly to mitigate traveling to and from your state agency to serve the employers (Anderson, 2001).

Modern marketing tools, such as the Internet, have also been quite effective in attracting new customers in a variety of geographical settings. Clients are capable of using a search engine (e.g., Google) to locate a variety of businesses that provide VR services. Although this may be useful in urban communities, organizations targeting rural communities may have difficulty in the effectiveness of this method. In addition, and as previously discussed, consumers and employers may be unaware of the services your agency provides or who has been assigned as the designated contact person to their rural community. Thus, a viable marketing option is simply through "word of mouth." Although this technique may seem apparent, the "word" of some respected people in the community can "make or break" a business. If you obtain a negative reputation in a rural community, chances are you likely to experience apprehension toward hiring PWDs.

Additionally, employees of VR organizations may consider volunteering or guest speaking at local events, where they will have an opportunity to explain the services provided to members of the community. A radio or newspaper advertisement may be another viable option for distributing information related to the VR services provided. Consider locating other organizations (e.g., center for independent living) to serve as a referral source. Lastly, a VRC should consider registering with the local chambers of commerce, advertise on local billboards, place advertisements on flyers, and connect with local business establishments either through direct contact with the employer or by requesting to place promotional material visible to their consumers.

Marketing Outreach to Employers

Prior to initiating marketing outreach, VRCs should conduct a labor market survey and attend job fairs and local community events. However, not all businesses in rural communities are able to take part in job-related events as many employers are involved with their day-to-day business operations. Thus, rehabilitation counselors should visit with businesses directly to introduce themselves and briefly discuss what services their agency provides and how they can be a viable asset. An interesting observation made by Geo (2012) identified differences between urban and rural communities. Particularly, successful outreach and job development in rural areas commonly consisted of the need for establishing personal relationships and networking partnerships. The primary difference between rural community connections and the business outreach models is the importance of personal rather than professional relationships (Geo, 2012). In many instances, counselor effectiveness was determined by who they knew, rather than what they knew, and the need for building trust as rural communities tend to be wary of outsiders.

To begin establishing a personal relationship and trust, a common yet apparent practice is emailing and/or calling the employer, thanking them for their time; this should generally take place within 24 h. Additionally, contact made should include specific highlights of the discussion in addition to follow up with questions the employer may have had during the initial meet and greet. This helps eliminate any preconceived notion they have of "outsiders" by providing a personal touch, which enhances professional relationships. Lastly, VRCs should reassure employers about the benefits their agency can offer. This occurs when the advocate/counselor emphasizes their experience in matching employers with quality and skilled personnel to meet individual business needs.

Marketing Outreach to Consumers

In order to develop successful VR service delivery in rural communities, it is essential to identify geographic and other related barriers that may impede consumers from contacting your organization for services. Earlier research, such as Arnold and Seekins (1997, 1998), has highlighted specific barriers that decrease the likelihood of successful VR outcomes, including poor economic conditions, lower educational levels, little or no public transportation, different consumer needs, service delivery methods and settings, and cultural reluctance of individuals to seek or accept help. The ability to reduce these identified barriers will assist organizations in providing and/or improving upon VR services provided in rural communities. Despite the effort in marketing services, if clients are reluctant to seek services because of cultural factors, the inability to locate transportation, or the inability to understand how their aptitudes, skills, knowledge, and abilities can assist them in finding and maintaining employment, then building a successful partnership between the VRC and client may be limited.

Therefore, to successfully market your services and ensure the outcome is fruitful for both the job seeker and employer, consider the following universal recommendations. Research the communities in which you will be providing services and determine what available resources exist. This includes assessing the community infrastructure (i.e., public transportation systems), demographic characteristics of the population, and general needs of the community. In addition, the labor market survey used to assess the current needs of employers also aids toward determining whether job openings are currently available that potentially match with the job seeker. Rehabilitation counselors who are marketing their services at local community events such as job fairs should have this information readily available. Prospective consumers are likely to follow up with the VRC if there is an inclination that successful job placement is likely to ensue. Lastly, determine at the onset the means of transportation the job seeker currently has. For those who reside in rural areas, a viable option may entail commuting to surrounding towns and potentially to its most nearby urban hub; taking into consideration the driving distance for this option is practical for the consumer. A strong marketing plan not only consists of providing flyers, business cards, and other marketing materials, but the ability to deliver the product and services for which the agency is marketing.

Summary

Today, vocational rehabilitation counselors are faced with unimaginable challenges when working with consumers and employers who reside in urban communities where resources are readily available. These often include but are not limited to assessing the needs of the consumer, assisting with resume development and job applications, interviewing skills, educating clients on how to find employment, and being an effective advocate for people with disabilities. When VRCs are assigned to rural communities and required to travel long distances to provide the aforementioned services, the following are likely to ensue: (a) unsuccessful alliance between VRC and employer as a result of limited contact, poor marketing plans/strategies, and failure to follow through with services promised and (b) clients are likely to stay unemployed and remain unaware of available job opportunities and how a vocational rehabilitation agency can assist toward meeting their employment goals. As such, the methods in which the VRC markets their agency and the services they provide are critical for counselor and consumer success and ultimately determine the direct outcome of case closure.

Discussion Questions

You have recently graduated from a vocational rehabilitation counseling program and have accepted a job offer located within an urban hub. Your caseload consists of working with clients from one surrounding city and three rural communities. The closest rural community from the agency in which you are employed is 30 min away followed by a 15-min commute to the remaining two rural districts. As you begin to develop your new caseload, discuss ways in which you would approach the following:

1. How would you begin to market your services to potential employers?
2. How would you begin to develop your caseload within your assigned rural communities?

3. Once you have successfully placed a client, what strategies would you use to ensure there is a strong fit between the employee and employer?
4. Considering the need for maintaining a strong partnership, what follow-up methods would you utilize with employers and your consumer?

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30

Implications of Workforce Innovation and Opportunity Act (WIOA) in Rural, Frontier, and Territory Communities

Allison R. Fleming and Noel A. Ysasi

Overview
The Workforce Innovation and Opportunity Act (WIOA) provides a substantial update to the 1998 Workforce Investment Act (WIA) legislation. While not solely targeting job seekers with disabilities, or those residing in rural areas, the implications of this refined and more streamlined approach to workforce investment have great potential to benefit constituents with disabilities living in rural areas. Comments by President Obama and Vice-President Biden during the signing ceremony underscored the goal of the WIOA legislation: providing opportunity for American workers to gain skills that are applicable for jobs where they can earn a living wage (Office of the Press Secretary, 2014). The economic landscape has changed drastically since the late 1990s when WIA was passed. Going to work with a high school diploma is no longer sufficient to obtain a good job; postsecondary education or training is significantly linked to job stability and earning capacity (U.S. Bureau of Labor and Statistics [BLS], 2014). The primary goals of WIOA are to connect training programs with the needs of employers, increase the accountability of training programs, and provide opportunities for on-the-job learning for youth and adults alike. For individuals living in rural, territory, and frontier communities, the economic picture is varied; some towns host industry and work opportunity and others do not. The primary features of WIOA that will be discussed in this chapter are the regional nature of WIOA and the implications for rural residents, along with implications for transition youth and veterans.

Learning Objectives
By the end of this chapter, the reader will be able to:

1. Understand the changes to service delivery associated with WIOA and the implications for rural, frontier, and territory communities
2. Explain how special populations such as transition youth, veterans, and clients of the workforce system will be impacted
3. Identify the benefits of WIOA to persons with disabilities living in rural areas

Introduction

The Workforce Innovation and Opportunity Act (WIOA) was signed into law on July 22, 2014, by President Barack Obama, and it took effect

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A.R. Fleming (✉)
Pennsylvania State University, Rehabilitation and Human Services, University Park, PA, USA
e-mail: apf508@psu.edu

N.A. Ysasi
College of Health and Human Services, Rehabilitation Services and Rehabilitation Counseling, Northern Illinois University, DeKalb, IL, USA
e-mail: nysasi@niu.edu

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on July 1, 2015 (US Department of Labor, n.d.). WIOA supersedes several previous laws guiding vocational rehabilitation and workforce services provided under the Workforce Investment Act (WIA) of 1998, The Wagner-Peyser Act, and the Rehabilitation Act of 1973, as amended. President Obama's comments regarding the WIOA legislation underscored the purpose of helping people, including those with disabilities, enjoy greater access to education, training, and employment opportunities and supports that will result in better employment outcomes in the future (Hoff, 2014).

Public vocational rehabilitation (VR) was established by legislation and has continued to be legislatively regulated for the entire history of the program. The services of VR agencies are well defined, focused specifically in assisting individuals with disabilities to prepare for, obtain, and maintain employment. VR services are considered "short term" in that once a client maintains employment for 90 days, his or her case will be closed. However, many individuals with disabilities require longer-term support even after securing employment. Many of the updates associated with WIOA encourage greater cooperation between the VR agencies and other related service providers, most directly educational systems, workforce systems, Medicaid, and state services for people with intellectual and developmental disabilities. In addition, provisions were enacted to clarify the definition of "competitive employment," close loopholes allowing for workers to earn subminimum wage, and emphasize the importance of agencies working directly with employers (Smith, Dillanhung-Aspillaga, & Kenney, 2016).

The updated regulations associated with the WIOA legislation have implications for state-level services to individuals with disabilities across VR, workforce, educational, and intellectual disability settings. The focus of this chapter will be to review the major changes associated with WIOA and then discuss the implications for rural areas. Particular client populations (e.g., transition youth, veterans) will also be highlighted.

History of the Workforce Innovation Act and Current Reauthorization of WIOA

The Rehabilitation Act Amendments of 1998 marked the first time a vocational rehabilitation initiative was imbedded within a workforce program, specifically the Workforce Investment Act of 1998 (WIA; P.L. 105-220). The law was intended to increase employment, retention, and earnings of participants, decrease welfare dependency, streamline administrative and service delivery functions, earmark resources, and enhance services for job seekers and employers (United States Department of Labor [DOL], 1998). Moreover, WIA encompassed (a) a "one-stop" delivery system, (b) contained a "work-first" approach stressing job-seeking and labor market reviews to assess the job seeker's readiness and needs, (c) provided direct assistance for identifying employment opportunities and job training to prepare for occupational readiness (i.e., interviewing and resume building), and (d) aided in developing appropriate skills to sustain employment (e.g., understanding work culture, appropriate dress attire, punctuality, conflict resolution, etc.). Prior to the signing of the law by President Clinton in 1998 and ultimately becoming effective in 2000, the development of this Act required nearly a decade of negotiating to restructure and unify the legislation before its enactment. The US Department of Labor, Employment and Training Administration (1998), outlines five titles structured within WIA as indicated in Table 30.1.

Since the Smith-Hughes Act of 1917, legislative efforts to enhance services for individuals with disabilities have been a historical battle. Though it became apparent through the enactment of WIA and inclusion of Rehabilitation Act Amendments, PWDs were an underrepresented population in dire need of government involvement that expanded and refined its current policies. To date, rehabilitation legislation has taken a century to evolve, yet new Acts can often hinder the population it is intended to serve. As will be seen in the proceeding section, the

Table 30.1 Workforce Investment Act (WIA)

Title	Services provided
Title I: Workforce Investment System	"One-stop" service delivery system whereby state and local communities deliver employment and training services within one common location, required accountability measures to ensure needs are being met by consumers, and provided array of services for disadvantaged youths, adults, and dislocated workers
Title II: Adult Education and Literacy Act	Adults are provided assistance in improving their educational and employment needs, to be self-sufficient, and improving educational attainment for their children
Title III: Amended the Wagner-Peyser Act of 1933	Integrates job search, job matching, and a one-stop system approach
Title IV: Rehabilitation Act Amendments	Amends programs within the Rehabilitation Act of 1978 and merges with state and local workforce development programs
Title V: General Provisions	Incentive programs for states exceeding performance standards under WIA, Adult Education Act, Perkins III, and transitional services

Workforce Innovation and Opportunity Act has provisions that undoubtedly improved upon WIA while simultaneously regressing to a period where educational requirements for state vocational rehabilitation agencies are no longer mandated to employ individuals with a graduate degree.

Workforce Innovation and Opportunity Act of 2014

On July 22, 2014, the passage of the Workforce Innovation and Opportunity Act (WIOA) was officially signed into law and became effective on July 1, 2015. The Act supersedes WIA, amends the Wagner-Peyser Act and the Rehabilitation Act of 1973, and is the first legislative reform in more than 15 years. A bipartisan and bicameral effort, WIOA was designed to provide job seekers with more access to employment, education, training, and support services to excel in the workforce while incorporating the traditional philosophy of a "best fit" model in which the job seeker's skillset is matched with that of the employer. WIOA (2014) was established to refine the workforce system by strategically improving collaborative efforts of the core WIOA and other federally funded programs that provide employment services, vocational rehabilitation, workforce development, and adult education and literacy programs. The following includes key elements of WIOA:

- The number of workforce investment boards are reduced.
- Youth with disabilities have increased opportunities to improve their skills in the workplace, provided with opportunities for career advising; VR agencies indicate how program funds are allocated for transitional services from secondary school to postsecondary education programs and competitive employment.
- Requirement of state and local plans (unified or combined state plan – discussed in the proceeding sections).
- Accountability measures are held to a higher standard for all core programs (outlined in proceeding sections).
- Expansion of employment and training services.
- Statewide set-aside philosophy – WIOA restores the statewide set-aside, but at the discretion of the state how allocation of funds will be distributed.
- WIOA establishes a strict budget for each fiscal year.
- Workforce development programs and states are accountable for meeting standards (i.e., successful employment outcomes) and collaborative efforts of state and federal evaluation efforts.
- Stronger emphasis on employer engagement (matching employers with skilled workers).
- Emphasizes competitive integrative employment (i.e., VR state plan gives priority to at-

risk PWDs of becoming unemployed unless provided with post-employment services).

Similar to WIA, the Workforce Innovation and Opportunity Act of 2014 consists of five titles but expands their services and requirements for states (see Table 30.2 for an overview of each title).

On April 2, 2015, the Department of Labor (DOL), Department of Education (ED), and other federal partnering agencies released five notices of proposed rule-making (NPRM) that delineates program-specific requirements of WIOA (U.S. Department of Education, 2016). These five NPRMs were made available for review to the public with most provisions taking effect on July 1, 2015. The plans were initiated by the ED, DOL, or both and consist of the following changes:

Table 30.2 Workforce Innovation and Opportunity Act of 2014

Title	Key provisions
Title I: Workforce Development Activities	Includes the adult, dislocated worker, and youth programs; primary emphasis is to increases access to, and opportunities for individuals to receive, the employment, education, training, and support services necessary to succeed in the labor market specifically for individuals who encounter barriers to employment (i.e., PWDs and low-income adults)
Title II: Adult Education and Family Literacy Act	Supports transition from adult basic education to postsecondary education, postsecondary training, or employment, assists immigrants toward the improvement of necessary skills (i.e., mathematics, learning to read, write, and speak English), includes civics education and workforce training; innovative supports for reentry into society by investing and developing programs for incarcerated individuals through education and career advancement and supports families and communities by encouraging educational and skill advancement of parents and their children to improve economic conditions for the family
Title III: Amendments to the Wagner-Peyser Act	Continuance of the current act, aligns with state employment services as outlined in the unified state plan, assessment of performance for agencies offering services, stronger emphasis on developing connections between service providers and employment agencies
Title IV: Amendments to the Rehabilitation Act of 1973	Aligns VR programs with other core programs of the workforce development system, strengthens VR program's focus on competitive integrative employment, and expands VR services for students and youths with disabilities for the purpose of achieving competitive integrative employment through enhanced coordination between VR agencies and local education agencies for individuals transitioning from school to postsecondary education and employment, and agencies who have special wage certificates allowing subminimum wages for PWDs; VR agencies must provide these individuals with career counseling and information and referral services to achieve competitive integrative employment
Title V: General Provisions	Compliance with Buy American Act; purchases of equipment or any product should only be American-made equipment and products; the head of federal agencies provides notice of any American-made products purchased for persons receiving financial assistance; prohibiting falsely labeled products as "Made in America"; transitional provisions; reduction of reporting burdens and requirements; and reporting on data

- NPRM (joint plan [ED and DOL]): Focuses on unified and combined state plans, assessments, and aspects of the "one-stop" system that falls under Title I

- NPRM (DOL only): Addresses the changes to the adult, dislocated worker, and youth programs as authorized under Title I
- NPRM (remaining three NPRMs under ED only): Addressed changes to the Adult Education and Literacy Act (outlined in Title II of WIOA), Rehabilitation Act of 1973 (outlined in Title IV of WIOA), State VR Services program and the State Supported Employment Services program, Section 511 (Limitations on the Use of Subminimum Wages), Client Assistance, American Indian Vocational Rehabilitation Services, Protection and Advocacy of Individual Rights, Independent Living Services for Older Adults Who Are Blind programs, and grant programs under Title II of the Rehabilitation Act

Unified and Combined State Plans

On March 2, 2016, the governor of each state was mandated to submit either a unified or combined state plan to the Secretary of DOL detailing the state's 4-year strategic proposal of their workforce system, a network of federal, state, regional, and/or local agencies which provide employment, education, training, and other necessary services contributing to successful employment outcomes (Washington State, Employment Services Department, 2014). For a state to be approved and receive funding, they must, at a minimum, incorporate six core programs which include the following: Adult Program, Dislocated Worker Program, Youth Program, Adult Education and Family Literacy Program, Employment Service Program authorized under the Wagner-Peyser Act, and the Vocational Rehabilitation Program. The *unified plan* encompasses the minimum aforementioned six core programs under WIOA, while the *combined state plan* includes all six core programs but comprises at least one or more of the following combined state partner programs (Table 30.3):

Table 30.3 Six core programs for unified plan

Core programs	Identified title
Adult program	Title I of WIOA
Dislocated Worker Program	Title I
Youth program	Title I
Adult Education and Family Literacy Act	Title II
Wagner-Peyser Act Program	Amended Title III
Vocational Rehabilitation Program	Title I of the Rehabilitation Act of 1973 – amended by Title IV

Note: Adapted from the Office of Management Budget (2016)

- Career and technical education programs authorized under the Carl D. Perkins Career and Technical Education Act of 2006
- Temporary Assistance for Needy Families Program
- Employment and Training Programs and the Supplemental Nutrition Assistance Program
- Work programs authorized under section 6 of the Food and Nutrition Act of 2008
- Trade Adjustment Assistance for Workers Programs
- Jobs for Veterans State Grant Programs
- Senior Community Service Employment Program
- Employment and training activities carried out by the Department of Housing and Urban Development
- Community Services Block Grant and training activities
- Reintegration of Ex-Offenders Program (Office of Management and Budget [OMB], 2016, p. 2–3)

To ensure the success of WIOA, a more collaborative and robust delivery system has been implemented, specifically the provisions of the unified and combined state plan. WIOA reforms planning requirements previously governed by WIA to promote collaborative efforts among programs, to expand service delivery efficiency, and to align employers with skilled individuals. Moreover,

> This reform promotes a shared understanding of the workforce needs within each State and fosters development of more comprehensive and integrated approaches, such as career pathways and

> sector strategies, for addressing the needs of businesses and workers. Successful implementation of many of these approaches called for within WIOA requires robust relationships across programs. WIOA requires States and local areas to enhance coordination and partnerships with local entities and supportive service agencies for strengthened service delivery, including through Unified or Combined State Plans. (OMB, 2016, p. 2)

Increased Role of VR Agencies in Transition

Perhaps the most discussed aspect of WIOA in VR agencies has been the requirement to increase the role of VR services in transition. The new regulation requires VR agencies to spend 15% of their funds on transition youth. This includes providing preemployment transition services and coordinating with local high schools and workforce development programs to support transition (Smith et al., 2016). What is a preemployment transition service? A preemployment transition service is a training or support that will help students before they leave high school, such as self-advocacy training, counseling on postsecondary options, work-based learning experiences, and other related services. Prior to WIOA, agencies were required to work with educational systems and provide consultation, as well as open cases for transition youth prior to graduation. This new regulation, particularly with the funding mandate, represents a significant increase in responsibility for VR agencies. One concern noted by several advocates (c.f., Hoff, 2014; Schroeder, 2014) is the possibility that the preemployment transition services could be provided in segregated settings; authors have suggested that advocates and service providers carefully monitor how these services are provided and push for integrated settings.

Preemployment transition services are conceptualized along a continuum and should be provided in collaboration with local education agencies (LEAs, e.g., school districts). Another major change is that preemployment transition services should be provided to any student who has a disability, not just students who have applied for and been made eligible for VR services. Students may choose to apply for VR when they need what is referred to as "individualized or intensive" services (Hoff, n.d.-a, n.d.-b; Hadsdell, Kisiel, Wiese, McVoy, & Wright, n.d.). These preemployment transition services are not a way to reduce the LEA responsibility for services or provide funding for services that are already provided by special education funds. Counselors or VR representatives should attend Individual Education Plan (IEP) meetings when invited, to allow for closer and more collaborative and seamless services for youth exiting high school. VR agencies and LEAs must update any agreements or memorandum of understanding documents to reflect these new requirements (Hasdell et al., n.d.).

Discussion Box

Arguably, one of the most critical changes for VR service delivery associated with WIOA was the requirement of increased financial investment (15%) in services for youth and preemployment transition services (PETS). While investing in youth and young adults at a critical point in their career development trajectory is useful and important, the fact that there has been no additional funding for VR services in light of this financial requirement is somewhat controversial. Like so many other questions about investment of public funds, this mandate begs the question, "how do we decide the best way to invest our public VR funding? Which people or populations are we prioritizing?" Previously, in public VR agencies, the priority was on individuals with "most significant disabilities" (MSD) identified through order of selection policies (OOS). These policies came about when agencies recognized that they did not have sufficient resources to be able to serve all potentially eligible persons with disabilities. State agencies used federal regulations to devise methods for prioritizing those with MSD first and then serving individuals with significant disabilities (SD) and, if resources permitted, those with nonsignificant disabilities (NSD).

However, with the passing of WIOA, agencies now have another mandate to prioritize. With no additional funding, the question of how to reallocate funds will be left to each individual state agency. If agencies were already meeting this funding mandate by spending 15% of their service dollars on PETS, then there will be no need to shift funds from other programs or priorities. For states that were not already meeting the minimum funding standard, decisions will need to be made as to where that money will come from. What will the ramifications of this legislative mandate be for adult consumers?

Limitations on Subminimum Wage

Section 511 of WIOA (effective July 2016) includes increased limits on work in segregated settings (e.g., sheltered) where workers earn less than minimum wage (Schroeder, 2014). Prior to the enactment of this limitation, under the Fair Labor Standards Act (FLSA; US Department of Labor, n.d.) some employers had special wage certificates (called 14c certificates) that allowed for paying workers less than minimum wage under specific circumstances. These circumstances included workers “whose earning or productive capacities are impaired by a physical or mental disability, including those related to age or injury, for the work performed” (US Department of labor, n.d.). The regulations highlighted workers with disabilities, homeworkers, and student learners as those who were covered under the FLSA. Section 511 of WIOA requires documentation that individuals with disabilities under the age of 24 have had the opportunity to work in an integrated setting before being placed in a segregated setting with pay that is less than minimum wage. Additionally, schools are prohibited from contracting with subminimum wage providers (Schroeder, 2014). Individuals who are placed in segregated settings (of all ages) must be offered services such as career counseling and referrals to promote competitive employment opportunities at regular intervals (Department of Labor, n.d.).

Formal Cooperative Agreements: VR-Medicaid-IDD Agencies

WIOA also requires that VR agencies enter into formal cooperative agreements with several of their key partners: Medicaid and those agencies providing services to residents with intellectual and developmental disabilities (ID/DD agencies; Hoff, 2014). The primary issue was that VR services are considered “short term” – with a case closure occurring once an individual has held a job for 90 days. Some individuals, particularly those with ID/DD, may need longer-term supports to maintain their employment. Often, these longer-term services were provided through alternative mechanisms such as Medicaid waivers or supportive services to individuals with intellectual and development disabilities (IDD) and severe mental illness (SMI).

Historically, VR agencies operated with relative independence, despite areas of overlap with other disability services and the workforce development service system. In many cases, workforce services were assisting individuals with disabilities, and Medicaid funds and staff in agencies serving individuals with IDD and SMI were supporting employment efforts. Relationships between these agencies ranged in levels of formality, from cooperative agreements to collaboration among providers at the local level. The unfortunate consequence was variability in the level of cooperation between VR service providers and those initiating long-term supports. With the new requirement, VR agencies must work more closely with agencies providing the long-term supports. Note that mental health agencies were not included in this provision, which is a point of contention with several advocates as this population also benefits from long-term supports (Hoff, 2014; Schroeder, 2014).

Role of VR in the Workforce System

The broad message sent from the legislature with the passing of WIOA to VR and the workforce system was to "be better partners" (Hoff, n.d.-a, n.d.-b). The primary service delivery mechanism under the workforce system is the One-Stop Career Centers (sometimes referred to as American Job Centers), where people can obtain access to employment opportunities and training programs in one place (Hoff, n.d.-a, n.d.-b). These services are overseen by local workforce boards and are available to those with and without disabilities. They are primarily individual-directed with staff acting as resources and providing minimal assistance. Historically, these centers were not accessible and not staffed in such a way to support the needs of job seekers with disabilities. For example, the centers were located in buildings with clear architectural barriers, without assistive technology to allow for use of the computers or communication devices (e.g., phones, fax machines), and staff were completely unaware of issues related to job seeking and career development for persons with disabilities. In fact, many people who identified with disabilities were directed to utilize VR or other special disability services instead, even if they had the skills and self-direction to benefit from what was available and did not necessary need additional assistance. To address this issue, in the early 2000s the department of labor began funding states to build the "disability program navigator" initiatives, and 42 states participated in demonstrations projects as of 2009 (Department of Labor, 2010). Disability navigators were intended to be employees within the workforce system who were available to help individuals with disabilities seeking services to navigate the centers, address accessibility issues, and expand the systems' ability to serve customers with disabilities through creating linkages and leveraging resources (DOL, 2009). While this initiative was discontinued prior to WIOA, it represented action toward the value of building a closer relationship between the VR and workforce development systems that is a large part of the WIOA regulations. In addition, VR agencies were required to include workforce partners in their Comprehensive Statewide Needs Assessments and State Plans to be filed with the Rehabilitation Services Administration. The new requirement is that the core programs (including VR agencies, workforce system, Wagner-Peyser, dislocated worker programs, youth programs, and other community partners) will develop a unified or combined state plan rather than separate plans as was the case before WIOA.

With WIOA, another key update is the strategic coordination of these two "core" programs (e.g., the workforce system and VR) in helping workers develop the skills necessary to succeed in our labor market (Department of Labor, n.d.). Local workforce boards must ensure sufficient services and providers for individuals with disabilities, accessibility of the One-Stop Career Centers (American Job Centers) must be assessed annually, and workforce boards must develop strategies to support career pathways for individuals with disabilities. These changes represent a major increase in the visibility and priority of disability in the workforce system. By ensuring that all systems are better situated to serve individuals with disabilities, it is anticipated that federal and state employment services can become more streamlined and efficient in helping all residents obtain high-quality jobs and careers. There will no longer be the need to separate out individuals with disabilities into special and segregated services unless they require higher intensity (e.g., supported and customized employment, funding for disability related services) only available through the VR agencies.

Changed Performance Measures

Another major theme in WIOA was the need to raise the level of accountability of employment and training programs (DOL, 2016). In 2016, core programs are subject to what are called "common measures" for measuring performance. These measures represent expanded data collection responsibilities, including specific indicators such as credential and skill gain of program participants and the effectiveness of services to employers. These common measures will be shared by all programs authorized under WIOA, and there will be adjustments applied based on local economic conditions. While some of the measures are the same as the previous requirements, there have been a few additions, and the timing of some measures has been shifted.

What will be measured? Well, as was the case before, workforce boards will need to report on the number of program participants who entered into unsubsidized employment and their retention. As a result of WIOA, this information will be collected after a lag of an additional quarter (e.g., entry into employment will be collected two quarters after exit instead of just one). This will require additional follow-up with program exiters and allow for a longer-term picture of the outcome of services. New pieces of information required for reporting include those related to skill gain and employment credentials. Long-standing employment data shows a clear connection between educational credentials (e.g., postsecondary employment) and earnings and employment stability (DOL, 2013). Boards will now need to report the percentage of participants who are enrolled in education leading to credential or employment and the percentage who obtain a recognized credential within 1 year of program exit (National Association of Workforce Boards, n.d.). For youth, the measure of literacy and numeracy gains has been eliminated, but new information must be collected about enrollment in education leading to credentialing and employment, as well as median earnings, and retention in training or employment with a 1 year follow-up requirement after program exit (National Association of Workforce Boards, n.d.). Finally, an indicator of the effectiveness in serving employers is now required, which is a completely new area of assessment under WIOA. The vision is that this data will be used to drive services and increase accountability of public programs so that taxpayers, policy makers, and consumers can better understand the value and effectiveness of employment and training services (US Department of Education, 2014). Workforce boards will be able to make informed decisions about contracts and alignment with outcomes under these common measures.

State VRC Educational Requirements

The state VR counselor minimum education requirements have been tied to, and fluctuated with, legislation over the years (Leahy, Chan, & Saunders, 2003). The 1992 amendments to the Rehabilitation Act resulted in an increase from a bachelor's degree to a master's degree for VR counselors. Particular service and activities were mandated to be performed by a qualified counselor (at the master's level), such as determining program eligibility and development of Individual Plans for Employment (IPE). However, estimates of VR counselors who did not hold a master's degree were as high as 30–50% even a decade after program implementation (Chan, 2003). With WIOA comes another change in educational requirements. Now, a master's degree is no longer required; instead, a counselor must hold at least a bachelor's degree from a field of study that is "reasonably related" to VR, including previously accepted disciplines such as rehabilitation counseling, social work, psychology and counseling, special education, as well as more ancillary fields such as business administration, economics, and human resources. While some feel that this reduced requirement opens the door of opportunity for prospective counselors with disabilities who were not able to obtain a master's degree with the help of a VR agency because of training limits (National Council on Independent Living, 2014), others lament the reduced training requirement and raise concern over the impact of services provided by professionals with inadequate preparation (McClanahan & Sligar, 2015). Since decades of role and function studies (c.f., Leahy, Chan, Sung, & Kim, 2013; Leahy, Szymanski, & Linkowski, 1993) have revealed that counseling is among the most common functions of a public VR counselor, it is of particular concern that individuals without counselor training will be considered qualified to provide this important service. Particularly for those trained in business administration, economics, and human resources, disciplines that are now included but were previously considered unrelated, counseling is not a function that individuals are trained to provide, nor are they familiar with the ethics and best practices required for maintaining safe and professional counseling relationships (McClanahan & Sliger, 2015). Particularly for those in these fields, it is unlikely that their educational preparation included a detailed study of the interaction between disability and work, as is the case with those who studied rehabilitation, disability, and other closely related fields. Research that is now somewhat dated revealed that counselors with a master's degree in rehabilitation counseling or a related field had better outcomes with individuals with most significant disabilities (Szymanski, 1991, Szymanski & Danek, 1992; Szymanski & Parker, 1989; Wheaten & Berven, 1994). Additional research is necessary under the new requirements to investigate the possible impact of counselor education on outcomes for VR clients, particularly those with the most complex barriers to work.

Linked to minimum education requirements is the Comprehensive System of Personnel Development (CSPD) that each state VR agency previously incorporated into their system of recruiting and training qualified staff. States had particular budgetary earmarks that they had to apply to help staff who did not meet the minimum education requirement access the necessary education to become qualified. In their state plan, they had to report the number of staff who did not meet the minimum educational requirements and explain the steps being taken to bring the staff up to the standard. This system allowed states who could not find qualified candidates to hire a bachelor's level person and then provide resources for them to obtain the necessary credentials. Counselors for special caseloads, such as bilingual/bicultural, clients who are deaf or hard of hearing, and those in rural areas where recruitment is difficult, often benefited from this program, and of course the benefit to the agency was that they had a mechanism for filling these critical vacancies. This also allowed for a career ladder, with staff hired as aides or administrative professionals who desired to move up to a counselor position to do so with the requisite training. With the lowered educational requirements, the CSPD program will not have the same importance and role within the VR agency.

Implications for Persons with Disabilities in Rural Areas

Even though the regulations and policies associated with WIOA are still emerging, there are several implications for persons with disabilities living in rural areas. Two populations that are particularly impacted are transition-aged youth and veterans, including those with disabilities and who are homeless. The following section highlights specific implications of WIOA for these groups.

Implications for Transition-Aged Youth

Leaving high school and transitioning to adulthood is a major undertaking for youth, particularly those with disabilities. This is true for youth living in all areas of the country, including rural regions. It has been widely acknowledged that youth with disabilities lag behind their peers in postsecondary educational attainment, employment, and independent living (Sanford et al., 2011). Studies of youth in rural areas indicate that their post-high school graduation aspirations are similar to their urban counterparts, but some of the environmental barriers serve as an additional level of complication for realizing their goals (Weiss, Hutchens, & Meece, 2012). For many, pursuing postsecondary education means they must leave their home communities. Just like other professions, there is a shortage of qualified teachers in rural areas and reduced opportunities for programming that provides an advantage for students when applying for college and qualifying for scholarships and other merit-based forms of assistance. Advanced placement, dual enrollment in college classes, career and college counseling, internship and work programs, mentoring, and a range of available math and science college preparation programs are some examples of opportunities not available in all rural schools (Weiss et al., 2012). Compounding this gap is the finding that students with disabilities in rural communities are less likely to have access to these programs even when they are available; save that for career exploration where students with disabilities reported higher levels of participation than their peers (Weiss et al., 2012).

For rural youth with disabilities, the enhanced requirement for preemployment transition services provided by VR agencies represents a major opportunity. One drawback of lack of access to some of the programs and services discussed earlier is that youth who are in the later grades (i.e., 11th or 12th) may not have a clear plan for what they will do after high school. The preemployment transition services are designed to be available to all students with disabilities, and general services such as planning for the future, learning self-advocacy skills, and identifying work opportunities early on are exactly the sort of programs that are included in this legislation and may fill a major gap in rural schools. In rural communities, if transition youth plan to stay after only attaining a high school credential, they will likely have limited work options and may be more vulnerable to layoff or cuts in employment because they have less experience than their older counterparts. One common challenge stated by counselors serving rural youth is the high reliance on disability benefits by the youth and their families. Some families have come to depend on the youth's benefit to cover basic needs for the family, such as food, rent, or medical care. Reliance on social security benefits is linked with region, where higher unemployment rates and concentrations of dangerous or physically demanding occupations (e.g., mining, manufacturing, agriculture) are associated with rural areas (McCoy, Davis, & Hudson, 1994). For youth, the issue of benefits is particularly startling, where if a young person starts receiving disability benefits because he or she is medically unable to work at 18, they are potentially signing up for a lifetime of poverty, unemployment, and higher risk for developing secondary mental and physical health conditions. Appalachia and the Mississippi Delta are two areas with historically elevated rates of poverty, disability, and reliance on public benefits (McCoy et al., 1994). Social Security, in recognition of this special risk for youth, has invested in special services and demonstration projects in an effort to help young people avoid dependence on benefits. Programs include job training and placement, as well as benefits and financial counseling so that young adults and families can understand the big picture of the impact of work on earnings, benefits, and overall financial self-sufficiency (Camacho & Hemmeter, 2013). WIOA provides additional opportunity to expand services to transition youth that are useful and culturally relevant in rural communities.

From the workforce side, there are additional efforts to increase the focus on youth. Specifically, "out-of-school youth" or those who have dropped out of high school prior to completion of a diploma are a special population noted under WIOA. The workforce system has increased priorities for helping these youth toward career pathways and opportunities for workplace learning and adopting these practices on a wider scale (National Association of Workforce Boards, n.d.). For youth with and without disabilities, increasing their ability to obtain meaningful employment opportunities at this important life stage is thought to set them up for greater financial self-sufficiency over the lifespan. Youth who can access useful job skills and connect with employers have much higher chances of staying in the workforce and

Case Study

Ms. Federline is a rehabilitation counselor working with Houghton County district in the Upper Peninsula of Michigan. The counselor has been tasked with collaborating with the local workforce board and neighboring schools to design and implement preemployment transition services (PETS) at the Houghton High School specifically for students with disabilities. The closest One-Stop Career Center is a neighboring town located in Hancock, MI. Approximately 400 students attend Houghton High School; however, the number of eligible students for vocational rehabilitation (VR) services has yet to be determined. Ms. Federline has been meeting with some of the school administrators and a representative from the One-Stop Career Center to decide what types of PETS programming might be most useful. The school already has a relationship with Michigan Technological University and offers advanced standing courses for students who qualify. Ms. Federline has been considering if perhaps additional programs might benefit noncollege seeking students, particularly students with significant disabilities.

The counselor and her service partners from the school and the One-Stop Career Center decide to offer career decision-making workshops to students and save most of the spaces for individuals identified as having a disability. However, WIOA requires programs to be available to anyone interested in attending. The One-Stop Career Center representative will come in to one of the sessions, explain what services are available for job seekers, and allow students to visit the center if school administration and parental consent are given. For students identified as having a disability attending the career decision-making workshops, school staff will work with the counselor to start the referral process for students and their parents for VR services.

Discussion questions:

1. What potential concerns may the counselor, school staff and administrators, and students with disabilities experience, if the workshop is available to anyone interested in attending?
2. Apart from workshops, what additional services can Ms. Federline implement so students with disabilities and their families may become aware of additional services available?
3. What programs might benefit noncollege seeking students with a disability?
4. What additional recommendations would you give Ms. Federline to enhance outreach and marketing services for students with disabilities?

earning reasonable wages than those who rely on low-wage, low-security positions.

Implications for Veterans

Frequently, veterans experience transitional difficulties post-discharge, and these challenges can be even pronounced for those residing in rural communities. Some of the more common barriers include finding employment that fits their military experience, adjusting to a newly acquired disability, and receiving credit for their educational benefits. Though veterans receive exceptional military training (e.g., supervising and training experience) which can prove useful in the civilian labor force, available employment opportunities remain elusive. This is often because veterans' qualifications do not translate well because employers do not understand military terminology used in resumes creating a situation of skill mismatch with jobs. As a result, many veterans frequently find themselves working in unskilled positions generating low pay. The new act has made significant efforts to improve transitional services for persons who have served in the Armed Forces and their spouses. To guarantee the outset of this Act, each state, as previously noted, submitted their unified or combined state plan. This plan outlined their strategic proposal, including a detailed explanation of how they will provide priority services for veterans through the collaboration of federal and local agencies to streamline their process and improve upon existing methods to ensure veterans are able to maximize their benefits. Specifically, including information on expanding state and local resources to support veterans in finding and maintaining employment and offering priority services for those that qualify. Priority service is a benefit which offers eligible veterans an expedited application as their claim is moved ahead of others for all DOL-funded programs (including WIOA). Under the Adult and Dislocated Worker program, "services" are administered to enhance opportunities for competitive integrated employment (i.e., training, education, vocational rehabilitation, etc.). Eligibility requirements include (a) having at least 1 day of active duty in the military (Army, Navy, Marines, Air Force, and Coast Guard), including Reserve units or National Guard activated for federal service, and (b) a veteran who did not receive dishonorable discharge status and was not deficient in basic skills. Veterans and their spouses also receive priority status if they are determined to be low income and demonstrate a need of additional education, career, and technical education or training to obtain and retain employment. Though the Bureau of Labor Statistics (BLS) in 2015 reported the unemployment rate was significantly low at 495,000 or 4.5 and 5.4 percent for males and females, respectively (DOL, BLS, 2016), a substantial number (i.e., 458,000 in 2007) have been removed from the workforce as a result of service-connected disabilities and/or from entering a postsecondary institution.

Generally, veterans enter postsecondary education for two reasons. First, the financial incentive of receiving approximately $1700 a month for those who served 3 years or more often operates as a source of income. Second, and as previously mentioned, veterans experience difficulties in finding employment related to their military work experience requiring the need to obtain a postsecondary degree for competitive employment. As a result, the Secretary of Labor and other federal agencies announced the new provisions under WIOA to conduct research and assess how previous work experience can translate into postsecondary education credit. This new provision will allow veterans to maximize their benefits through the Montgomery G.I. Bill and Post-9/11 Veterans Educational Assistance and potentially further their educational attainment to a graduate degree.

To further improve conditions for veterans, the Department of Labor released a statement indicating the requirement of enrolling programs which serve homeless veterans within the public workforce system through American Job Centers (AJCs). The primary purpose is to connect this population of veterans with workforce programs to ensure successful employment outcomes and thus reduce homelessness. Programs which are federally funded through the Wagner-Peyser Act or any WIOA title program (i.e., services for adults and dislocated workers) are required to implement this policy and submit performance information (i.e., participant characteristics, services, and outcomes). Apart from the requirement of grantees tracking and reporting outcomes, (a) programs are to provide trainings to staff on the various AJC services offered and their enrollment criteria, (b) homeless veteran programs and AJCs are to facilitate strong working relationships and learn what each program offers, and (c) programs are to ensure counselors present during the enrollment of a homeless veteran into a workforce program (DOL Publication No. 03–16).

Broader Potential Impact and Additional Policies

A major impact for rural communities of the WIOA changes is the initiatives allowing flexibility to regions and local workforce boards. It is clear that the labor market of rural, frontier, and territory communities is drastically different than more populated regions. The increased emphasis on local workforce boards and their mandates are an important opportunity for rural areas. Specifically, boards are required to connect with local employers, create innovative strategies to engage employers and promote effective services for their local area, complete comprehensive labor market analyses with information that is specific to their local region, and engaging partners in their communities.

The process of performing a labor market survey is central to the scope of practice for a rehabilitation counselor (Commission on Rehabilitation Counselor Certification, n.d.). A labor market survey is the process of gathering information about the availability of a given job in general and in the local economy. It helps to answer questions about the existence of jobs, the availability, minimum requirements and eligibility, and the typical range of pay and benefits offered for the job in question (Lee, 2010). Information is also collected about the rate of turnover and openings. For rural, frontier, and territory communities, it is essential to have this kind of information prior to pursuing skill or credential development, which can help with career decision making. The local labor market is often limited, and individuals may need to decide between available positions or relocating for a position if so desired. In addition, one can decide if the time and monetary investment in training is worthwhile given the expected pay range and benefits. Regional information, such as educational and skill levels of workers, will also become available as a result of these analyses. One potential benefit of having this information readily available is that it can be shared with businesses as a way to help them recognize the human potential that resides in a given region or community.

The mandate to connect with local employers and increase services directly to employers also represents a major opportunity for rural communities. There is a push for local workforce boards to connect employers and industry with education programs to produce workers with desirable skills and qualifications (National Association of Workforce Boards, n.d.). In communities with specific industry (e.g., agriculture, manufacturing, service), it is possible for employers to help educators understand what training and preparation they desire workers to have and even collaborate on building certificate programs and on-site job experiences so that both parties benefit. A direct outcome of these kinds of relationships is that graduating students are more qualified for available positions, and industry has a greater applicant pool to draw upon for hiring needs.

Summary and Conclusions

The Workforce Innovation and Opportunity Act (WIOA) took effect on July 1, 2015. It represents a significant update to previous legislation that guided workforce development and employment services for individuals with and without disabilities in the USA. WIOA is based on the idea that in a changing economic landscape, we need to shift our approach to ensuring that American workers are prepared for real, paying jobs that are available in their local or regional community. In order to accomplish these goals, the emphasis is on data-driven decision making, accountability, and greater collaboration across systems that serve individuals with and without disabilities all across the country. The emphasis on regional workforce boards and connections with local employers represents a significant opportunity for rural residents. Stipulations to prioritize services to special groups, including veterans and youth and young adults with disabilities, are also very relevant to rehabilitation counselors and related professionals. At the time of this writing, the regulations are available, and agencies, boards, and the rehabilitation community are working to alter the way service is provided to accommodate the new priorities in WIOA. Additional data will allow for greater evaluation of the impact of this important legislation.

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Learning Exercises
Self-Check Questions

1. Discuss the implications of WIOA on the employment of VR counselors in rural areas. How do you think the changed educational qualifications might impact agencies? What about clients?
2. Explain 2–3 benefits of WIOA for youth and young adults with disabilities.
3. Explain 2–3 benefits of WIOA for veterans.

Field-Based Experiential Assignments

1. Explain the importance of the Workforce Investment and Opportunity Act (WIOA) to someone who does not know anything about the law. See if you can answer questions and help the person understand the significance.
2. Visit a One-Stop Career Center in your local area, and learn what services are available to job seekers.
3. Interview a VR counselor who was practicing at the time WIOA was passed. Ask him or her about what has changed since WIOA became law.

Multiple Choice Questions

1. What is the difference between a unified and combined state plan?
   (a) Unified state plan includes all six core programs but comprises of at least one or more combined state partner programs.
   (b) Unified state plan encompasses the minimum of six core programs while the combined state plan comprises of six core programs and at least one or more partner programs.
   (c) The governor is only required to submit a unified state plan and not a combined state plan.
   (d) Differences between the unified and combined state plan are determined by the type of core programs for each.
2. When was the Workforce Innovation and Opportunity Act signed into law?
   (a) March 7, 2013
   (b) October 21, 2014
   (c) July 22, 2014
   (d) July 1, 2015
3. Why was the Workforce Innovation and Opportunity Act established?
   (a) To refine the workforce system?
   (b) Increase accountability among federally funded programs?
   (c) Provide job seekers with greater access to employment, education, training, and support services?
   (d) All of the above
4. What is the minimum educational attainment for a vocational rehabilitation counselor employed in a state VR agency?
   (a) Associate's degree.
   (b) Bachelor's degree.
   (c) Master's degree.
   (d) State agencies determine the minimum educational attainment.
5. According to the new provisions of WIOA, state vocational rehabilitation agencies are able to employ rehabilitation counselors with what type of degree?
   (a) Associate's degree
   (b) Bachelor's degree
   (c) Master's degree
   (d) Doctorate degree
6. What is a common occurrence for veterans seeking employment?
   (a) Skill mismatch
   (b) Employers not understanding military terminology used in resumes
   (c) Lack of skilled training
   (d) Insufficient educational opportunities
   (e) Both a and b

Key

1. B
2. C
3. D
4. D
5. B
6. E

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Americans with Disabilities Act in Rural America: A Case Study

31

David T. Beach and Kristin L. Maxwell

Overview

The United States is a country of small towns. While many of these small towns may be in varying distances to larger metropolitan areas, each has its own unique culture and its intention to be self-sufficient and supportive of its members. The case could be made that this independent spirit is what has made the United States a great nation, yet it should also be noted this same independence and self-sufficiency clashes with federal oversight and policy. The Americans with Disabilities Act (ADA) is an example of such an occurrence. The ADA encompasses the complex dance of applying national policy in such a way that allows local communities control to implement changes that best serve the community and the spirit of the law.

When it was passed in 1990, the Americans with Disabilities Act (ADA) established equal access as a civil right to individuals with disabilities. Each of the five titles was groundbreaking in their own right. The five titles of the Americans with Disabilities Act are

- Title I: Employment
- Title II: Public Services
- Title III: Public Accommodations and Services Operated by Private Entities
- Title IV: Telecommunications
- Title V: Miscellaneous Provisions

Each of these provisions had a profound impact on the nation and the ability of persons with disabilities to have equal access. Despite profound national impact, relatively few people were aware of and understood this civil rights law.

With respect to small rural communities, the ADA can be a challenge. The challenge with the ADA implementation in small rural communities is that it forces compliance at the expense of local areas where there may be a small or nonexistent perceived disability population in the community. The ADA takes an approach that focuses on broad access and universal design, while the approach of the small town may be to respond to issues on a case-by-case basis. An argument made by a small town may be "Why go to the expense of building a ramp if there is no one in the community to use it?" Instead, when a member of the community develops a disability requiring accommodation, this same town may come together and ensure accessibility of the environment to fit his or her unique needs. While there are obvious

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D.T. Beach (✉)
University of Kentucky, Disability Resource Center, Lexington, KY, USA
e-mail: dtbeac1@uky.edu

K.L. Maxwell
University of Kentucky, Rehabilitation Counseling Program, Lexington, KY, USA
e-mail: klmaxwell@uky.edu

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arguments to this approach, it captures the heart of the debate of how small towns offer access in a world of dwindling public resources.

This chapter will provide a brief overview of the Americans with Disabilities Act (ADA) and its subsequent amendments of 2008, examine common barriers to the compliance to the ADA in rural areas, provide recommendations for improved compliance with the ADA (including issues of accessibility) for rural America, and posit future implications that may impact compliance with the ADA specifically in Kentucky. First, the chapter offers the Commonwealth of Kentucky a lens through which to understand the Americans with Disabilities Act and its implications in rural communities. Examples from Kentucky are woven throughout the chapter to contextualize the idea of the Americans with Disabilities Act and its implementation in rural communities, such as those in rural Kentucky.

Learning Objectives

Upon completion of this chapter, the reader will be able to:

1. Name and describe the titles and provisions of the Americans with Disabilities Act of 1990 and subsequent amendments of 2008.
2. Describe common barriers to compliance with the ADA in rural areas.
3. Identify potential ways to improve compliance with the ADA in rural areas.

Americans with Disabilities Act

The Americans with Disabilities Act (ADA) was enacted in 1990 as a public law and was considered a monumental, even watershed piece of civil rights legislation. Modeled after Section 504 of the Rehabilitation Act of 1973, the ADA prohibits discrimination of persons with disabilities in nearly every societal domain and is intended to provide equal access and full participation within society. The ADA specifies a clear set of anti-discriminatory and federally enforceable standards that allow individuals with disabilities access to such societal

Table 31.1 Definition of disability

Sec. 12102. Definition of disability
As used in this chapter:
… (1) Disability
The term “disability” means, with respect to an individual
(A) A physical or mental impairment that substantially limits one or more major life activities of such individual
(B) A record of such an impairment
(C) Being regarded as having such an impairment (as described in paragraph (3))
(2) Major life activities
(A) In general
For purposes of paragraph (1), major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working
(B) Major bodily functions
For purposes of paragraph (1), a major life activity also includes the operation of a major bodily function including, but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions
(3) Regarded as having such an impairment
For purposes of paragraph (1)(C):
(A) An individual meets the requirement of “being regarded as having such an impairment” if the individual establishes that he or she has been subjected to an action prohibited under this chapter because of an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity
(B) Paragraph (1)(C) shall not apply to impairments that are transitory and minor. A transitory impairment is an impairment with an actual or expected duration of 6 months or less
(4) Rules of construction regarding the definition of disability
The definition of “disability” in paragraph (1) shall be construed in accordance with the following:
(A) The definition of disability in this chapter shall be construed in favor of broad coverage of individuals under this chapter, to the maximum extent permitted by the terms of this chapter
(B) The term “substantially limits” shall be interpreted consistently with the findings and purposes of the ADA Amendments Act of 2008
(C) An impairment that substantially limits one major life activity need not limit other major life activities in order to be considered a disability

(continued)

Table 31.1 (continued)

(D) An impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active
(E)
(i) The determination of whether an impairment substantially limits a major life activity shall be made without regard to the ameliorative effects of mitigating measures such as
(I) Medication, medical supplies, equipment, or appliances, low-vision devices (which do not include ordinary eyeglasses or contact lenses), prosthetics including limbs and devices, hearing aids and cochlear implants or other implantable hearing devices, mobility devices, or oxygen therapy equipment and supplies
(II) The use of assistive technology
(III) Reasonable accommodations or auxiliary aids or services
(IV) Learned behavioral or adaptive neurological modifications
(ii) The ameliorative effects of the mitigating measures of ordinary eyeglasses or contact lenses shall be considered in determining whether an impairment substantially limits a major life activity
(iii) As used in this subparagraph
(I) The term "ordinary eyeglasses or contact lenses" means lenses that are intended to fully correct visual acuity or eliminate refractive error
(II) The term "low-vision devices" means devices that magnify, enhance, or otherwise augment a visual image

As taken from the ADA of 1990 and subsequent ADAAA of 2008

venues (Sales, 2014). The Americans with Disabilities Act defines disability in order to describe who the ADA is intended to serve and protect (see Table 31.1), in addition to extending many rights to those who are "regarded as" having a disability (see section on "Americans with Disabilities Act Amendments Act of 2008").

Titles and Provisions of the 1990 Americans with Disabilities Act

The Americans with Disabilities Act consists of five titles, Title I, II, III, IV, and V. These five titles and subsequent amendment ensure equal access to community participation for individuals with disabilities, who live in the United States.

Title I: Employment The Title I provision of the ADA outlines equal access to employment for individuals with disabilities and makes it illegal for employers to discriminate against individuals with disabilities in any aspect of employment (hiring process, job training, promotion, or firing). Title I also requires that employers with 15 or more employees make reasonable accommodations (see Table 31.2) for employees with disabilities who are qualified to perform the essential functions of the job, unless such an accommodation would cause the employer undue hardship (see Table 31.3).

Title II: Public Services Title II provides individuals with disabilities equal access to public services and also extends provisions related to transportation as described in Section 504 of the Rehabilitation Act of 1973 (Sales, 2014). Title II prohibits discrimination on the basis of disability, as it pertains to the access of any state or local government services or programs, as well as public activities that would otherwise be accessible to all individuals within the community. Public services and entities may include access to public housing programs and postsecondary education, the use of a post office or postal service, polling locations (voting), libraries, streets, and courthouses. Title II also ensures equal access to public facilities such as telephones, public spaces (such as buildings), and bathrooms. Further, this title of the ADA establishes guidelines for the accessibility of public transportation. It requires that all vehicles used for public transportation that navigate a fixed route be accessible to all individuals with disabilities, including those who use wheelchairs (e.g., a wheelchair lift is required for public transportation vehicles). The law also prescribes alternate, accessible forms of transportation, if public transit vehicles are not accessible. Finally, Title II requires that all public transit rail forms (such as subway system or trains) have at least one accessible car.

Title III: Public Accommodations and Services Operated by Private Entities Title III provisions prohibit discrimination on the basis of disability in "public accommodations and commercial facilities," including private entities who own places or establishments that affect community commerce.

Table 31.2 Definition of reasonable accommodation

Subchapter I – employment
Sec. 12111. Definitions
As used in this subchapter:
… (9) Reasonable accommodation
The term "reasonable accommodation" may include:
(A) Making existing facilities used by employees readily accessible to and usable by individuals with disabilities
(B) Job restructuring, part-time or modified work schedules, reassignment to a vacant position, acquisition or modification of equipment or devices, appropriate adjustment or modifications of examinations, training materials or policies, the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities

As taken from the ADA of 1990 and subsequent ADAAA of 2008

Table 31.3 Definition of undue hardship

Subchapter I – employment
Sec. 12111. Definitions
As used in this subchapter:
… (10) Undue hardship
(A) In general
The term "undue hardship" means an action requiring significant difficulty or expense, when considered in light of the factors set forth in subparagraph (B)
(B) Factors to be considered
In determining whether an accommodation would impose an undue hardship on a covered entity, factors to be considered include:
(i) The nature and cost of the accommodation needed under this chapter
(ii) The overall financial resources of the facility or facilities involved in the provision of the reasonable accommodation; the number of persons employed at such facility; the effect on expenses and resources; or the impact otherwise of such accommodation upon the operation of the facility
(iii) The overall financial resources of the covered entity; the overall size of the business of a covered entity with respect to the number of its employees; the number, type, and location of its facilities
(iv) The type of operation or operations of the covered entity, including the composition, structure, and functions of the workforce of such entity; the geographic separateness or administrative or fiscal relationship of the facility or facilities in question to the covered entity

As taken from the ADA of 1990 and subsequent ADAAA of 2008

Title III identifies 12 subsets of such public accommodations and commercial facilities. These include places of lodging not existing for the purpose of residence (i.e., a hotel, motel, or inn), establishments that serve food or drink (i.e., restaurant or bar), places of entertainment or exhibition (i.e., theater, stadium, or concert hall), places of public gathering (i.e., auditoriums, convention centers, or lecture halls), establishments of sales and rentals (i.e., grocery store, shopping center, hardware store, or specialty goods), service establishments (i.e., hospitals, banks, gas stations, pharmacies, laundry service, repairs, or banking), specific public transportation spaces (i.e., terminals or depots), places of recreation (i.e., parks, amusement parks, or zoos), places of public display or collection (i.e., galleries, libraries, or museums), places of education (i.e., elementary, secondary, postsecondary, nursery, or private schools), social service establishments (i.e., centers for daycare or eldercare, homeless shelters, or food pantries), and places for exercise and recreation (i.e., gymnasiums, bowling alleys, or sports clubs). Title III established standards related to "readily achievable" (see Table 31.4) physical environmental barrier removal for existing venues of public accommodations or commercial facilities, as well as standards for alterations or construction of new buildings. Examples of ADA compliant modifications include doors of a specified width, grab bars in bathrooms, specifications related to wheelchair accessible ramps, addition of Braille to elevator buttons, website accessibility, curb cuts, van accessible parking spaces, and lowered drinking fountains. Other examples of barrier removals and modifications and possible solutions to barrier removal can be found in the *Checklist for Readily Achievable Barrier Removal* (Adaptive Environments Center, 1995; see https://www.ada.gov/checkweb.htm).

Title IV: Telecommunications Title IV of the ADA "requires telephone and Internet companies to provide a nationwide system of interstate and intrastate telecommunications relay services that allows individuals with hearing and speech disabilities to communicate over the telephone" (https://adata.org/learn-about-ada). Technology and services that assist in telecommunications

Table 31.4 Definition of readily achievable

Subchapter III – public accommodations and services operated by private entities
Sec. 12181. Definitions
As used in this subchapter:
… (9) Readily achievable
The term "readily achievable" means easily accomplishable and able to be carried out without much difficulty or expense. In determining whether an action is readily achievable, factors to be considered include:
(A) The nature and cost of the action needed under this chapter
(B) The overall financial resources of the facility or facilities involved in the action; the number of persons employed at such facility; the effect on expenses and resources; or the impact otherwise of such action upon the operation of the facility
(C) The overall financial resources of the covered entity; the overall size of the business of a covered entity with respect to the number of its employees; the number, type, and location of its facilities
(D) The type of operation or operations of the covered entity, including the composition, structure, and functions of the workforce of such entity; the geographic separateness or administrative or fiscal relationship of the facility or facilities in question to the covered entity

As taken from the ADA of 1990 and subsequent ADAAA of 2008

include a telecommunication device for the deaf (TDD) and telecommunication relay services, whereby individuals who have a hearing or speech impairment are able to communicate with those who do not (and vice versa). Telecommunication relay services may be two-way, such as from a TDD to an individual who does not use such a device (and vice versa), or three-way such as a third party operator who relays information via speaking or typing (via voice or manually) from one party to the other. Title IV also includes requirements for closed captioning of verbal content that has been funded by the federal government, such as public service announcements.

Title V: Miscellaneous Provisions Title V delineates processes and procedures related to enacting the ADA, including procedures related to litigation and filing complaints, provides additional clarification of the law, describes agency and public assistance for carrying out the law, specifies agency assistance in implementation of the law (e.g., Equal Employment Opportunity Commission, Attorney General, Secretary of Transportation), and describes awarding of grants or contracts for assistance in implementing ADA requirements.

Americans with Disabilities Act Amendments Act of 2008

In 2008 the Supreme Court overturned two court cases (*Sutton vs. United Airlines*, *1999*; *Toyota Motor Manufacturing*, *Kentucky*, *Inc. vs. Williams*, *2002*) with a ruling that limited the definition of disability by reducing the activities that could be considered a major life function, effectively limiting those that could be protected by the ADA. Under the court's interpretation of the ADA of 1990, courts ruled against extending provisions of the ADA to individuals with cancer, diabetes, human immunodeficiency virus (HIV), mental illness, and epilepsy (https://www.ada.gov/nprm_adaaa/adaaa-nprm-qa.htm, 2014).

In response to the conservative rulings by the Supreme Court that went against the original intent of the law, a bipartisan effort in the Congress responded to these rulings and resulted in the Americans with Disabilities Act Amendments Act of 2008 (P.L. 110–325; ADAAA of 2008), which was signed into law by President George W. Bush. The ADAAA of 2008 "revised the definition of "disability" to more broadly encompass impairments that substantially limit a major life activity, [and] specified that assistive devices, auxiliary aids, accommodation, medical therapies and supplies have no bearing in determining whether a disability qualified under the law" (Sales, 2014, pp. 38–39).

The ADAAA of 2008 also established that an individual who is "regarded as" having a disability refers to "how a person has been treated because of an actual or perceived physical or mental impairment (that is not transitory and minor), rather than on what an employer may have believed about the nature or severity of the person's impairment" (https://www.ada.gov/nprm_adaaa/adaaa-nprm-qa.htm). However, individuals who are protected by the "regarded as" section of the law are not

Research Box 31.1

Title of the Research
The ADA, 20 Years Later: The Kessler Foundation/National Organization on Disability 2010 Survey of Americans with Disabilities.

Objective
This survey was one administration of a longitudinal survey, administered six times since 1986, that measured the differences between individuals with disabilities and individuals without disabilities on several indicators of quality of life. These domains included employment, poverty, education, healthcare, transportation, socializing, going to restaurants, attendance at religious service, political participation, and satisfaction with life. The 2010 administration of this survey assessed three additional domains of technology, access to mental health services, and overall financial situation. The research also included measures on the ways in which the Americans with Disabilities Act impacted individuals with disabilities related to these indicators.

Method
This study employed a cross-sectional, basic sampling technique using random-digit dial method for a household, telephone survey of adults, ages 18–64, with disabilities ($N = 1001$ or an adult who was within the household who was able to serve as a proxy which was equivalent to 10% of the population of those sampled with disabilities) and without disabilities ($N = 788$). The survey also utilized an "oversample of people with disabilities in the labor force" (p. 160; $N = 315$) in an online survey, to increase the accuracy of estimations for that population.

Results
The Kessler Foundation/National Organization on Disability 2010 Survey of Americans with Disabilities found that despite the passage of the Americans with Disabilities Act (ADA) in 1990 and the subsequent ADA Amendments Act of 2008, there was ongoing, consistent, and substantial differences between those with and those without disabilities in most domains measured, with the exception of improvements in the domains of education and political participation. The study also found that the economic environment of recession impacted individuals with disabilities more so than those without disabilities, evidenced by larger differences between the two groups in the domains that were measured during this time.

Conclusion
There continues to be a significant gap between individuals with and without disabilities on the indicators of quality of life, as measured by this study. While the ADA appears to have aided in decreasing the gap in education and political participation between individuals with and without disabilities, other indicator discrepancies appear to have remained unaffected. Other general findings of this study suggested that there was no one domain that was "the" indicator of quality of life for individuals with and without disabilities. Instead, the survey determined that indicators that contribute to quality of life are as varied as the uniqueness of the individuals who were surveyed and were only partly determined by any one characteristic. More accurately, it is likely that a composite of personal characteristics, type of disability and extent of disability, and contextual factors in which a person lives, as well as other factors not measured, contribute to the impact of indicators on quality of life.

Demonstrate your understanding of this study as it applies to rural communities.

The Kessler Foundation survey included a question about whether the ADA had "made your life better, worse, or made no difference" (p. 144). Only 23% of the respondents indicated that the ADA had made life better. *Sixty-one* percent of the respondents stated that the ADA made no difference, 7% indicated that they had never heard of the ADA, and 4% stated that the ADA had made life worse. As this was a nationwide sample of the United States, we can assume that people in both urban (highly populated) and rural (sparsely populated) areas were polled.

How do you think these numbers would change if they only reflected rural areas or small cities, towns, and communities? Do you think the ADA would have more or less of an impact for individuals who live in small, rural communities? How and why?

entitled to the reasonable accommodation, unlike those individuals who have disabilities as defined by the "disability" definition of the ADA.

One State's Journey: Kentucky as a Case Study in ADA Compliance

This section looks at the state of Kentucky in general, as one case study example of the implementation and compliance of the ADA in rural areas. To better understand the context of Kentucky's current status, data related to the population, economic, workforce, and health of the population is provided below.

Kentucky Population Composition and Characteristics

The Commonwealth of Kentucky (pop. 4,413,457) is a rural state that has struggled with ADA compliance. Kentucky is a largely rural state with three metropolitan areas (Louisville, Lexington, and Northern Kentucky – a Cincinnati, OH suburb), all within a short drive from each other, configuring what is often referred to as the "golden triangle." This "golden triangle" is surrounded on the west, south, and east by large rural areas comprised of relatively small communities. Kentucky is ranked 26th in population among the 50 states and 24th in population density with 109 persons per square mile. The median household income is $43,342, and 18.9% of the population lives below the poverty level. In the 2014 census, 83.5% reported having a high school diploma, and 13.2% reported being uninsured (United States Census Bureau, 2016).

Unique to Kentucky is its local governance. While a relatively small state in area, the state has 120 counties, half of which have populations below 20,000 people (United States Census Bureau, 2016). This means there are 120 county governments, 120 county judge executives (the highest elected county official), 120 county clerks, etc., each with their own unique culture and history, which has significantly impacted the ability for the Commonwealth to implement broad and complicated laws, such as the ADA.

Health of Kentucky

In terms of health, Kentucky perennially ranks at the bottom of most state rankings. According to the Kaiser Family Foundation (2016), the state was ranked 45th in life expectancy at 76.0 years, with 24.3% of the population reporting being in poor physical health and with 34.6% reported being in poor mental health. Kentucky was ranked 16th in drug-related deaths and third in the percentage of the population that smoke tobacco on a regular basis. Smoking tobacco increases the risk of disability linked to a number of health conditions, including respiratory disease, cardiovascular disease, type 2 diabetes, and cancer (Center for Disease Control, 2016). The Kaiser data also confirmed a high incidence of obesity and diabetes for residents of Kentucky, which are both risk factors for disability. Such statistics do not point to a healthy citizenry.

Economy and Employment in Kentucky

The “golden triangle” has fully recovered from the Great Recession through its concentration of automobile assembly manufacturers, major shipping and logistics providers (such as those that provide trucking and warehousing services), and healthcare. In contrast, rural areas that have historically relied on agriculture and coal, which tend to have severe boom (i.e., times of great wealth, production, demand, and increased employment opportunities) and bust cycles (i.e., times of decreased yields, low demand, and decreased employment opportunities), have had more difficulty bouncing back economically.

Kentucky also once had a flourishing textile industry, but most factories dwindled after the passage of the North American Free Trade Agreement (NAFTA, 1994). NAFTA allowed for reduced or eliminated tariffs on goods traded between the signatories of the United States, Canada, and Mexico. With the ability to trade at reduced or no taxes, goods (such as agricultural products) could be procured from less expensive sources, resulting in less demand in areas where they were produced at higher prices. This left communities without steady, skilled, and semiskilled jobs which in turn had an impact on local business owners who sold goods and services to the employees of these manufacturers. The loss of these industries and the unpredictability of the coal and agricultural economy have left many rural Kentucky communities with limited resources and a crumbling infrastructure.

The data clearly indicates some challenges faced by rural Kentucky, as many factors impact local, regional, and state level decision-making. These factors must be taken into consideration when reviewing whether a state like Kentucky chooses or does not choose to comply with the ADA. The issue is much more complicated and complex in nature and will be explored throughout the chapter.

Common Barriers to the Compliance with the ADA in Rural Areas

While the Americans with Disabilities Act (ADA) impacted the United States at large, it had substantial implications for rural areas and communities. Since the passage of the ADA, several barriers to its compliance have been identified. Common barriers to ADA compliance in rural areas include barriers related to physical accessibility, transportation, and compliance with ADA Title I Employment provisions.

Physical Accessibility

A criticism of the ADA was that, like its predecessor (Section 504 of the Rehabilitation Act), it was an unfunded mandate. Local government and states were expected to develop transition plans to comply with the various titles of the ADA, with no additional funds or resources to implement the plans. Obviously, this is a significant barrier because many rural communities have limited resources to maintain primary services to its citizenry; and the additional costs of curb cuts, ramping, remodeling, and accessible bathrooms may be overwhelming to budgets. This becomes a perceptual barrier, because citizens and legislators may believe that only a few people with mobility or physical disabilities reside in any given locale, so investing in accessibility may be considered a major expense that only benefits a very small or nonexistent subset of the community. While arguments can be made that an aging baby boomer population will increase the need for an accessible environment and that an entire community can benefit from being physically accessible, a federal mandate for this significant expense can lead to resistance and contempt toward the disability community.

Barriers to Transportation

As has been previously discussed in Chap. 3, transportation for persons with disabilities living in rural areas has a long history of not meeting the demand for service. For individuals to take full advantage of the provisions of Titles I, II, and III of the ADA, they must have reliable and accessible transportation to benefit from the inclusive nature of the law. For example, an individual with a disability cannot benefit from the equal access to employment if they do not have transportation to get to a job. From an ADA perspective, however, the focus is not on providing disability-related services. As a civil rights law, it is focused on ensuring equal access to public or private services in existence. For many communities, equal access to transportation is not an issue *because there is no readily accessible public transportation system for these communities*.

For those localities fortunate to have transportation systems in place, there are still significant barriers to providing accessible transportation. As is a common theme, cost is an issue that remains an obstacle because vehicles must be retrofitted with lifts or purchased new with modification. Both are expensive options. Upkeep and maintenance of the equipment is also a significant expense, as the many moving parts are prone to breakdown frequently. Training of personnel in effective interactions and the safe unloading and loading of wheelchair users may also be a challenge, as drivers may have minimal experience with persons with disabilities.

Barriers to Compliance with Provisions Related to Title I: Equal Employment

In their promotion of the Americans with Disabilities Act (ADA), advocacy groups of persons with disability demanded full inclusion in society, which can only occur if persons with disabilities are able to work and earn wages commensurate with their peers. The ADA was intended to level the playing field by not allowing businesses to exclude applicants because of the presence or

Discussion Box 31.1: Business and Public Service Physical Accessibility

Since its inception, the ADA has been criticized for its increased costs to businesses, both large and small. Fueling this criticism, business owners complain they had to heighten expenses to make their businesses meet the letter of the law, even though the potential population was relatively small or even nonexistent. Businesses also complained of frivolous lawsuits brought forth by persons with disabilities that had not even requested accommodation to utilize the services of their businesses. Their belief was that this was being done so attorneys could get their fees paid by the business should the case be resolved in the plaintiff's favor (Los Angeles Times, 2000). Actor/Director/Business Owner Clint Eastwood was an earlier champion of language that would require persons with disabilities to notify businesses of access issues prior to initiating legal complaints (Los Angeles Times, 2000).

While these changes never materialized, even with the ADA Amendments Act of 2008, efforts continue by various groups to interject "notice" proposals in the ADA to protect businesses. One such effort was the ADA Notification Act, introduced by US Congressman Duncan Hunter in 2009. According to Congressman Hunter, businesses would not be relieved of their responsibility to meet the requirements of the ADA, but instead "….it provides businesses with a reasonable opportunity to evaluate alleged violations and make the corrections before the legal process can begin." The legislation also claims to protect businesses from unnecessary costs related to "frivolous" lawsuits (Congressman Duncan Hunter Website, 2009).

What are your thoughts regarding this issue for businesses? Is it fair for businesses to be required to make costly physical changes that may never be utilized? What are the caveats of requiring persons with disabilities to provide notice to a business prior to initiating a complaint? What would be the long-term impact on the ADA if a notification act was passed?

How would notification laws possibly impact businesses located in rural areas? If these notification laws extended to government buildings and schools, how would that impact access for individuals with disabilities living in rural areas?

implied presence of a disability (ADA, 2000, 2008). Employment, in general, is often a challenge in rural areas, as these areas tend to have more limited labor markets than metropolitan areas. Primary employment areas in rural sectors tend to be heavily comprised of agricultural and natural resources and a variety of low-skilled service industry positions. Many of the available jobs either are extremely physically demanding or require a set of specific technical skills, which do not always match the employment needs of persons with disabilities. The remaining, less physically demanding jobs are very competitive. Traditionally, when the competitive employment sector is flooded with qualified applicants, individuals without disabilities are more likely to be selected for employment over individuals with disabilities (Bauer & Growick, 2003). This is part of a larger and ongoing trend in employment of individuals with disabilities (e.g., underemployment) in the competitive labor market (Bricout & Bentley, 2000).

Impact of Rural Culture on ADA Compliance

The ADA was developed through years of advocacy of persons with disabilities seeking to have full access and be treated as equals in society. This phenomenon was a break from the traditional societal views of a life of dependency and lower social status for persons with disabilities.

In rural areas, where independence and self-sufficiency are highly appreciated, people who have physical skills and abilities, acquired technical knowledge, and a hard work ethic are considered to be of a high value. Often there is also an expectation that every person will contribute to the community or family unit (Bauer & Growick, 2003). Individuals who do not have the physical skills or capabilities to contribute to the family unit or the community may be marginalized and made to feel as if they have fewer rights, because of his or her perceived dependence on the community or family unit. This is a major barrier, especially when the culture suppresses the individual from advocating for his or her right to access and equality. This stifled advocacy for oneself prevents the accurate representation of the presence of disability in the community, causing local leaders and members to assume that there are few or no persons with disabilities in the community.

Barriers to ADA Compliance in Kentucky

Physical access Access to government buildings and removal of physical access barriers have been a struggle in rural Kentucky. Government services and some small businesses historically were located in non-accessible buildings, many of which were built by the Tennessee Valley Authority in the recovery period of the Great Depression. Compounding the issue of ADA compliance, rural communities that were often established as transit and commercial centers that shipped goods to larger metropolitan areas were located on or near a river. Buildings constructed near rivers are designed in such a way that floodwaters will not damage the buildings and are typically built high off the ground. Buildings set higher than ground level are not often easily accessible to wheelchair users or those with mobility impairments. Some accessibility was provided by Kentucky's judicial branch that modernized courthouses (to be accessible to all individuals) across the state during the late 1990s and early 2000s. In many rural communities, the courthouse is the centerpiece of the community. These new courthouses were built to ADA specifications and greatly increased physical access for all in a positive manner.

State Level Support and Technical Assistance On a statewide level, the mandated office designated to coordinate and enforce compliance related to all titles of the ADA was initially located in the office of the governor, until 2002, when it was moved to the Education and Workforce Development Cabinet. This had a significant impact on the influence of the office as the coordinator no longer had a direct line of communication to the governor, reducing the ability of ADA-related issues to garner attention and priority. While the position is still appointed by the governor, it has been minimally staffed since its inception and has had little budget to reach out to local communities, which may indicate where there have been several Department of Justice findings against rural communities in counties related to physical access to public services and buildings (Department of Justice, 2016). The most egregious of these findings was the Department of Justice investigation of jails and government buildings in 23 Kentucky counties designed by Architecture Plus for lack of compliance with the Americans with Disabilities Act (Messenger-Enquirer, 2005).

Voting In many rural areas of the state, voting can also be a challenge for persons with disabilities. Many polling sites in small communities were located in a business, such as the local general store, a church, or a community center. In some cases, the polling place was in the only building in the community, so options were limited. Unfortunately many buildings were not physically accessible, and poll workers did not have training on how to assist individuals with visual or hearing impairments. Persons with disabilities were effectively being denied their voice in the local community because they were being denied their right to vote through the inaccessibility of their environment (physical and social). This went largely unnoticed until the 2011 general election in which Secretary of State, Allison Lundergan Grimes, worked cooperatively with county clerks to ensure equal access for persons with disabilities to polling places. While these efforts greatly increased access, they had an unintended consequence. Polling places were removed from some communities because of a lack of an accessible polling site in the local community, requiring members of those communities who wanted to vote to travel longer distances to vote.

Transportation To say that public transportation in Kentucky is a challenge is a vast understatement. Public transportation is not readily available except in the metropolitan areas, and even those services are limited. Some of the larger towns have small bus routes, many of which *do* serve individuals with disabilities. However small bus route service area and hours of operation are limited, making it difficult to utilize the services for reliable transportation to and from a job.

Employment As can be noted by the high unemployment rate for persons with disabilities in Kentucky, competitive employment opportunities remain a challenge (Kentucky Career Centers, 2016). While the reasons for these elevated unemployment rates are complex, there is little evidence of support of the employment provisions of the ADA by either the executive or legislative branch. Kentucky is not currently an Employment First state, there are minimal efforts to promote the ADA or employment for persons with disabilities, and subsequently the ADA hardly gains notice by businesses or the public at large.

Related to employment and equal, nondiscriminatory access to employment, Kentucky's public Vocational Rehabilitation (VR) program has not had the funding to meet its federal match requirements in several budget cycles and currently institutes order of selection, prioritizing individuals with the most severe disabilities first and has had to place eligible consumers who do not meet the criteria for most severe disabilities on a waiting list for services until money became available (H.B. 303 Free

Conference Committee Report, 2016). Insufficient funding hampers the ability of the VR program to conduct outreach and education activities to employers regarding ADA Title I responsibilities. The approach implemented by VR and its service providers has been one that emphasizes positive aspects of creating a diverse workforce through hiring persons with disabilities and further explaining the benefits of employing individuals with disabilities, rather than taking a legalistic, adversarial approach toward employers. Once the person with a disability is hired, these agencies offer support to assist the employer and employee and navigate any disability-related issues. A legalistic approach may be viewed as coercive or forceful by employers and may not be effective for hiring and retaining employees and a positive employment environment. There is a concern that the forceful approach of the law may cause employers (unintentionally or intentionally treat employees) in a negative manner, especially if they feel obligated to hire because of a law, and businesses will be more likely to invest in someone they hired for their abilities.

Impact of Ongoing Factors that Influence ADA Compliance in Rural Areas

Diminished Budgets and Competing Priorities

As rural America comes to grip with how to comply with the provisions of the ADA and improve access to its citizens, several factors exist that will likely impact future compliance efforts. One obvious example is the diminishing financial resources and the aging infrastructure of rural communities.

If one was to poll public office holders, community planners, and the many government employees involved in the planning and development of rural areas, the results would likely show strong support for the concepts of the ADA. While some of those polled may argue that the ADA was not necessary or it was an overreach of power by the federal government, it is unlikely there would be many arguments made that persons with disabilities shouldn't have access to their community or to employment. The problem is that equal access is not free. Curb cuts, ramps, and level sidewalks have a cost, as do many other things that comprise a small communities' budget. While community leaders may want to create accessible spaces, they often face difficult decisions regarding the spending of funds and consideration of the greater good for its citizens. While not complying with the ADA is a violation of a federal law, the more immediate needs related to other budgetary concerns may trump the potential risk of legal action.

Compounding this issue is that many rural communities rely on property and sales tax to provide the majority of their budget. As the populations of these towns and counties have remained stagnant or decreased, so too does the tax base and property values. Local leaders, elected by a majority vote, are assigned the task of providing for the needs of the community, and the budget may be barely enough to provide basic services, leaving little money for improvement or infrastructure upkeep. In their view, the needs of a minority of the population may be put to the side or compromised, so that other city services can continue or infrastructure be addressed (Hudson, 2010).

Aging Populations in Rural Areas

Budgeting and community planning become more critical as the minority eventually becomes the majority, as residents of rural communities increasingly become comprised of older adults. Colello (2007) attributed the growing percentage of older adults to the "out-moving" of younger adults and "in-moving" of older adults that had previously lived in the area and had moved away. Increasing populations of older adults increase the likelihood of an increase in disability as part of the natural aging process, which would equate to an increase in the need of accessible streets, buildings, and transportation. As this trend continues, Hudson (2010) believes that the older adult population will actively advocate for their right to better access to buildings and public services.

Availability of ADA Expertise

One other critical factor to ADA compliance in rural areas is an availability of expertise regarding the law itself. The ADA is a very technical law, especially when considering physical accessibility requirements. Complete knowledge of the various aspects of the law requires expertise in architecture, engineering, human resource policy and law, assistive technology, and the impact of disability on functioning. This is a skill set few possess, and those that do possess such knowledge command consultant fees out of the reach of most rural budgets. There is no licensure or certification to establish the expertise of someone who purports to be an ADA expert. The National Institute on Disability, Independent Living, and Rehabilitation Research has funded the ADA National Network, comprised of ten regional technical assistance centers, to provide information and education materials to businesses, communities, postsecondary education entities, and individuals with disabilities (ADA National Network, 2016). Their websites and expertise serve as valuable resources to communities; however their resources are limited in their ability to provide individual consultation with small communities.

Rural communities seeking expertise regarding the ADA have no clear manner by which to identify a credible and qualified advisor that is able to offer individualized, comprehensive technical assistance to small communities. Questions for which advisement may be warranted include: How will communities that want to improve access know how to do so appropriately? How will communities know the difference between meeting the minimum ADA Standards and Universal Design, which focuses on creating accessible spaces that meets the needs of everyone? Fundamentally, without access to reliable information and expertise, how can rural communities be expected to comply in a manner that truly meets the requirements of the law *and* the actual needs of their citizens?

Rural Kentucky: Impact of Ongoing Factors that Influence ADA Compliance

These factors, when compared to the example of Kentucky, highlight the complexities for the path forward for ADA compliance in small town America. As noted in a newspaper article analyzing 2010 Census data, the Estep (2011) found rural areas of Kentucky are seeing a slow decline in population, even though the state population grew 6% from the previous census. Not only is the rural population shrinking, it was losing young families, with many young adults that go away to college never coming back to their home community.

For those that remain, there are few opportunities for employment, as rural counties of further distance from the “golden triangle” have unemployment rates nearly double the state average (Kentucky Career Center, 2016). Drug and alcohol abuse are rampant, with Kentucky ranked 7th in opioid death rate, 27th in non-medical pain reliever use, and 26th in the number of citizens reporting illicit drug use, with a disproportionate report of percentage levels higher in rural areas of the state (Kaiser Family Foundation, 2016). This has led to a correspondingly elevated rate of crime related to the manufacture and trafficking on drugs (Tunnell, 2006). This is slowly eroding the workforce of qualified employees and discourages businesses to expand or grow in these areas. The rural areas are in danger of losing a generation, which has repercussions, because young adults should be the generators of industry and the economy. This loss of population takes away growth and resources, preventing rural communities from addressing many issues, including the ability to address physical access.

Rural Kentucky is also impacted by a dearth of knowledge and expertise available for communities seeking to improve access to comply with the provisions of the ADA. As stated earlier in the chapter, it appears policy makers in Kentucky have taken an approach focusing on meeting minimal compliance requirements of the ADA. The office of the State ADA Coordinator has been minimally staffed and chronically underfunded. This has impacted the office's ability to conduct outreach to rural communities or to even respond to requests for information. A review of the Kentucky League of Cities and the statewide chamber of commerce, both important informational resources for rural areas, reveals minimal information regarding persons with disabilities and nothing related to physical access. With the state not taking any significant stance in support of the ADA and no other real source of individualized technical assistance for small communities, the state's rural communities seem to have minimal local options to seek assistance in fulfilling the provisions of the ADA.

Recommendations for Improved Compliance in Rural America

The drafters of the Americans with Disabilities Act (ADA) seemed to understand the monumental changes the law would require, which they appeared to counterbalance by allowing communities to develop transition plans to set priorities as to how the various provisions would be met with future financial resources. The enforcement side of the law was even minimized to the extent that it was difficult for the complainants to receive financial reward due to court action. Ensuring compliance has typically been based on investigations that occur because of an accessibility complaint filed against the community. This relies on members of the local community who have disabilities to file complaints, but culture forces may work against them advocating for themselves for risk of being ostracized by those around them. This complaint-based enforcement also forces the community to take an adversarial role when working with members of the disability community.

But there has to be a better way. After 25 years, many states have yet to fulfill the promise of the Americans with Disabilities Act, and it is clear the current approaches are not affective. This section will discuss some recommendations to improve compliance with the letter and intent of the ADA.

Financial Incentives

A carefully prepared financial incentive plan could encourage communities in meeting the required ADA provisions. This type of incentive could take several approaches.

Grants for rural community accessibility projects This type of funding could potentially prioritize and support accessibility initiatives for rural communities. This could potentially fund capital projects or efforts to overhaul policies and procedures or inaccessible websites in an effort to meet ADA requirements.

Pros of grants for rural community accessibility projects:

- Address specific accessibility needs in a community
- Create a partnership with local disability community
- Do not require cash outlay by the local area
- Would likely raise awareness of ADA

Cons of grants for rural community accessibility projects:

- Need significant federal or state funds to have an impact
- Will likely need an award process, which could be cumbersome and expensive
- Require new funding streams in a time when government is seeking to decrease its spending

Rebates, reimbursement, or loan forgiveness This type of approach would either pay back or forgive future payments to communities who complete targeted provisions of the ADA. The communities could have a loan or bond forgiven, forgiveness from future tax payments, or any other future cost that could be leveraged.

Pros of rebates, reimbursements, or loan forgiveness:

- Do not require new funds
- Require only minimal oversight in administration
- No grant process

Cons of rebates, reimbursements, or loan forgiveness:

- Negative overall impact on a federal or state budget, depending on the loan or payment forgiven
- Request initial cash outlay by the community for which the community may not have available

Low-interest loans This option would be similar to the rebate/reimbursement option, but instead of payments being returned or forgiven, communities could apply for low-interest loans to complete ADA-related projects.

Pros of low-interest loans:

- Do not require funds upfront by community
- Address specific disability needs in the community with cash infusion
- Have a net zero impact on budget, as funds loaned will be repaid

Cons of low-interest loans:

- Require availability of funds from either state or federal sources
- Possibility of a cumbersome loan application process and oversight
- Default risk by rural communities

Consultation funds In this option, rural communities would have access to funds to purchase the services of a consultant to advise on community planning related to the ADA.

Pros of consultation funds:

- Lower cost option
- Can provide more comprehensive planning

Cons of consultation funds:

- Communities may not have funds to pay for projects in accessibility plan.
- Need for a qualification process to determine the qualifications of appropriate consultants.

It should be noted that each of these financial incentives should not be considered mutually exclusive options. Multiple incentive programs could be offered to assist rural communities with complying with the provisions of the ADA. Regardless of the methodology, it is important for rural communities to have access to fiscal resources to address accessibility.

Development of Technical Assistance Resources

While the Department of Justice (DOJ) offers an information line (https://www.ada.gov/taprog.htm) and a multitude of technical assistance documents and materials, no true resource exists to provide individualized consultation to rural communities. Because of the investigation responsibilities of the DOJ, communities may be reluctant to reach out to federal agencies for fear of raising suspicion. Also, the culture of the community may place more value on the expertise of someone they know at a more local level.

In terms of creating this expertise in every community, there is certainly ample information available to educate local leaders; however it is unrealistic to expect local communities to have the capability and staff to develop the expertise to meet the many requirements of the law, when the sheer nature of being a leader in a small town may require them to wear a multitude of professional hats. Rural communities need resources, and they need them to come from resources they trust. There are several strategies that could be utilized.

State Level States could be incentivized to increase their expertise and outreach to rural communities regarding ADA compliance and the concept of integration. This could be accomplished by increased funding to state-level ADA offices.

Pros of state-level implemented strategies:

- No new administrative level
- Available expertise possibly known on a local level

Cons of state-level implemented strategies:

- Extra costs may be burdensome to state or federal budgets.
- State level resources may not be trusted by local communities.

Private or not-for-profit organizations Communities often belong to private or non-profit groups, such as a league of cities or association of counties that provide services to communities and advocate the behalf of their members. In this option, grants could be made available to these organizations to provide ADA Technical Assistance to the rural communities.

Pros of private or non-for-profit organizations as resources:

- May be able to individualize services.
- Information comes from a trusted source.
- Develops awareness of ADA in the organizations.

Cons of private or non-for-profit organizations as resources:

- New funding stream and process.
- Not all communities in need of assistance belong to these groups.

Area Development Districts (ADDs) ADDs serve as a partnership among regional areas of a state, working together to develop region-wide strategies, provide human services, develop a workforce, and administer various grants (Northern Kentucky Area Development District, 2016). ADDs could be provided grant funds or other incentivized to develop and provide consultation programs to rural counties.

Pros of Area Development Districts (ADDs) as resources:

- Administrative structure already in existence.
- ADDs have knowledge of the region.
- Could be individualized by the ADD.

Cons of Area Development Districts as resources:

- Possible onerous grant process.
- Regional political factors may impact availability of funds to all rural communities in need.
- Lack of available ADA expertise available to ADDs.

Outreach to the Rural Disability Community

One of the unique issues of rural communities is its culture, which may not be respectful, accepting, or aware of the needs of individuals with disabilities. Because the value of the rural community is typically tied to "usefulness" and the ability to contribute, persons with disabilities are often not viewed as having a value in the community. While this may be more unconscious or unintentional, it still leads to the marginalization of the disability community as a whole. Rural towns need to reverse this cultural aspect and reach out to the disability and aging community, as the community can benefit as whole if it is inclusive of the unique views, needs, and perspectives of all its citizens.

To change this cultural phenomenon, communities will have to proactively reach out to the disability community, which will be a difficult task, as the persons with disabilities living in rural areas are often isolated. Rural leaders will need to go where this population is likely to frequent or centers of the community where people tend to gather. This could include the public health department, local physicians, libraries, community colleges, school systems, and the legal system. Agricultural extension

Case Study 31.1: JJ

JJ was a star athlete enjoying his junior year of high school in 1990, in a small town in southern Kentucky with a bright future in front of him. He excelled in multiple sports, receiving multiple scholarship offers to play baseball and football at the division I college level. All of that changed in an instant when he was involved in an accident on the football field, suffering a spinal cord injury, leaving him as a person with quadriplegia, with no function in his arms and legs.

Once his medical condition stabilized after an extended stay in acute and then subacute rehabilitation facilities, he returned to his small town. Because this was prior to the Americans with Disabilities Act, very few of the buildings in his town were accessible to someone using a wheelchair. He could not see a local doctor because his building was not accessible. He could not shop at many of the local stores because they did not have accessible entrances, nor could he cross the street because there were no curb cuts. While his high school was supposed to be wheelchair accessible because of requirements of the Rehabilitation Act of 1973, he was unable to access many of the classrooms, the gymnasium, or even the football field where he was once a star. It was not that the community did not care; they did not know how to meet his needs. Because the community was so small, they had never encountered someone with his significant physical limitations. But they wanted to help. JJ was so popular and well liked in his community people were compelled to help him.

So, his family and members of the community worked together to remove the many barriers that impacted his access. It started at his church, where his father was a pastor. They built a ramp that would allow JJ to enter the sanctuary and made sure all doorways and hallways were accessible to his large wheelchair. The school sought experts from the Office of Vocational Rehabilitation for assistance in becoming more wheelchair accessible. School officials worked with JJ to make sure he had equal access to classrooms, offices, or any place a nondisabled student could go. They paved an accessible pathway to the football field and ensured him access to the student section so he could cheer on his teammates. The family worked with the local leaders to make the community more accessible by advocating for curb cuts and ramps to public facilities, and his proudest day was when he was able to enter a previously inaccessible polling place and cast his own vote. In some cases, local businesses made their entrances and buildings more accessible.

After his senior year, JJ went away to a relatively close midsize state university, where he majored in journalism. He came back home and worked for the local paper for many years as a sportswriter. This required him to travel to neighboring school athletic fields and gymnasiums, which in turn made these school systems evaluate their accessibility.

By the time JJ left his position at the newspaper and went to Lexington to work in a marketing position, his advocacy efforts had a profound difference on making many of the communities in the area more accessible and exhibited how a community can rally around its citizens with disabilities and be truly inclusive.

offices and AgrAbility programs would also be good resources for outreach to an aging and/or disability community. Police departments often serve as the face for a community and may prove valuable in identifying individuals with disabilities. Human service workers are also resources in this endeavor, because they too have relationships with a wide variety of the citizens and are often aware of the acute needs of those in the community. The religious community can also serve as a valuable and motivated partner, as spirituality often is a pillar of the community and many churches seek to be good civic citizens as well, providing services such as food and transportation to those that may be impaired due to a disability.

After identifying this group, the local communities will need to engage them in civic planning to ensure their needs are heard and hopefully met through careful planning and the building of trust. Culture is often very difficult to overcome, but it is critical for local rural community leaders to reach out so that the true intent of integration for persons with disabilities can continue to move forward.

The Curious Case of Kentucky: What Is Next?

In this chapter we have outlined the many challenges related to compliance with the intent and provisions of the ADA in the state of Kentucky. Some of these challenges are a result of uncontrollable factors such as the topography, the economy, demographic shifts – to name a few. But evidence is also present that Kentucky has not embraced the civil rights legislation that is the ADA and has in some instances ignored the requirements of a law that seeks to promote the quality of all citizens with varying degrees of abilities.

The intentionality of noncompliance is complex, and multiple arguments could be made on either side. Is this a rural state flexing its muscle in regards to its independence by delaying or ignoring federal requirements? Does it not care about well-being and quality of life for a significant proportion of its population? Could it be that there aren't enough resources available to assist communities in implementation and the other emergent factors are too great to warrant the necessary effort?

Regardless of the reason, Kentucky must carve a path forward to increase its awareness of, and compliance with, the ADA. But many questions remain, and many physical and attitudinal barriers exist. The first challenge will be finding a person, office, or entity to carry the disability rights flag into the political and social arenas to promote the advantages of integrating persons with disabilities. State agencies that provide services to individuals are administered by governor appointees who are often beholden to the direction of that office for fear of losing their job. The state-level disability advocacy groups often focus primarily on services and issues related to their specific disability area rather than general integration and ADA compliance. The state-independent living centers are prime candidates to head this effort, but are significantly hampered by limited resources, with only two Part C centers and one Part B center operating in the state.

Assuming a group or entity takes up the banner of inclusion and ADA compliance, significant efforts will be necessary to conduct outreach and education to community leaders, businesses, members of the state legislature, members of the community, postsecondary education, service providers, etc. There would also have to be a monumental outreach through a multitude of community partners to reach the rural disability community, who up to this point have never been considered or contacted. Because of their isolation in rural areas, people with disabilities have not had the opportunity to communicate with each other and advocate for their rights.

If this outreach was successful and mobilized action by the various parties, politicians, and communities to make the decision to fully support the ADA in rural Kentucky and the community of individuals with a disability advocated for their rights, there is still the matter of available expertise to consult these communities. Because of a lack of attention paid on a statewide level to the ADA, there is little expertise to draw upon in terms of civic planning. Therefore, funds would have to be made available to hire consultants to assist in the planning process. These consultants would not likely be from Kentucky, because there is often not a substantial presence of ADA expertise available locally. Rural communities may be resistant or reluctant to trusting or valuing the input from such an outside consultant or expert.

Assuming the accessibility plans to make the rural were developed and approved by all of the necessary groups and agencies, these plans would still have to be executed. To execute these accessibility plans, funds must be available to make the necessary changes, and as we have discussed, many rural communities in Kentucky barely have the necessary funds to maintain basic services. So we have taken a very long journey toward integration only to end up at a very predictable place. Without substantial financial resources, rural communities will struggle in providing for the provisions of the ADA.

This is not to say that it would be impossible to accomplish ADA compliance in rural Kentucky; it is merely to illustrate the substantial effort and resources necessary to meet intent of the law. The implementation of the ADA was intended to be inertial in that states/communities/counties/colleges would incrementally implement non-discriminatory policies and improve physical accessibility, which would provide greater access and bring about more change. For states and communities that chose not to take that approach, there is no quick fix, as there is no magic financial bullet to fix the various issues. For communities to comply with the ADA, they must take on the approach many cities and towns took before them, which is to address the ADA requirements, one ramp, one accessible entrance, or one curb cut at a time.

Resources

1. Federal Department of Justice Americans with Disabilities Act information page – www.ada.gov
2. Americans with Disabilities Act National Network – adata.org
3. Americans with Disabilities Act Guide for Small Towns, U.S. Department of Justice – www.ada.gov/smtown.htm
4. Americans with Disabilities Act Coordinator Certification Training – www.adacordinator.org
5. Job Accommodation Network – askjan.org
6. Kentucky Appalachian and Rural Rehabilitation Network – karrn.org
7. Research and Training Center on Rural Rehabilitation – rtc.ruralinstitute.umt.edu

Learning Exercises

Self-Check Exercises

1. List and explain the titles and provisions of the Americans with Disabilities Act (ADA).
2. What is the impact of the ADA in rural areas?
3. How might rural areas in other areas of the country (such as Montana, Texas, Alaska) differ from Kentucky?
4. What are three ways to improve ADA compliance in rural areas?
5. What three federal resources for ADA compliance?

Field-Based Experiential Assignments

1. What resources are in your state for rural areas, regarding Americans with Disabilities Act (ADA) compliance specifically related to (a) accessibility, (b) employment, and (c) voting? You are encouraged to explore these questions using the Internet.
2. Who would you talk to in a rural city about ADA compliance issues (say, e.g., if a building was not accessible to enter or use the restroom in and you want to talk with someone at a city level for this)? Who deals with ADA compliance in small towns and cities in rural areas, and what do they do? Place a call to three different rural communities, and find out information on building and public space's physical accessibility and ADA compliance within each small town or city. To assist in finding a small town, you can go to http://www.city-data.com/, and search the state and the phrase "smaller cities, towns, and villages" or "very small towns and villages." Next, in an Internet search engine, search the town and state that you have selected, and add "mayor's office" to your search. The mayor's office, city halls, and the city clerk are all good places to place your phone call to and start your investigating! You can also do an Internet search for the city ADA coordinator. If there appears to be no city ADA coordinator, you will want to start at the lowest level (closest to city level) – such as Public Works, Planning and Zoning, or whoever does

inspections for buildings. At a higher level, you can contact the county or the Area Development District. Does the city that you selected have an ADA coordinator? Who would you speak with if you had trouble accessing a public building and have a disability? Would you speak with the mayor and/or city council? What is the process you would go through to discuss modifications to buildings for accessibility?

3. To better understand physical accessibility, select a public building in your community, and use an ADA accessibility checklist, such as the ADA Checklist for Existing Facilities that can be found at http://www.adachecklist.org/doc/fullchecklist/ada-checklist.pdf. Select at least five items from each of the four priorities (i.e., Approach and Entrance, Access to Good and Services, Toilet Rooms, Additional Access) to assess and report on. What are the implications? If you have not assessed a public place in a rural area, how do you think things may be the same or different?

Multiple-Choice Questions

1. Which of the following best describes the Americans with Disabilities Act of 1990?
   (a) It is designed to prohibit discrimination against individuals with disabilities.
   (b) It is designed to be and is federally enforceable.
   (c) It was amended in 2008 to expand rights to be afforded to those who are "regarded as" having a disability, though reasonable accommodation is not required if the person does not meet the definition for disability.
   (d) All of the above.
   (e) None of the above.
2. Which title of the Americans with Disabilities Act has to do with equal access to communication, including closed captioning for Public Service Announcements?
   (a) Title I
   (b) Title II
   (c) Title III
   (d) Title IV
   (e) Title V
3. Which title of the ADA provides individuals with disabilities equal access to public services and extends provisions related to transportation as described in Section 504 of the Rehabilitation Act of 1973?
   (a) Title I
   (b) Title II
   (c) Title III
   (d) Title IV
   (e) Title V
4. Which of the following is not a common barrier to the compliance with the Americans with Disabilities Act?
   (a) Physical accessibility
   (b) Transportation
   (c) Educational accommodations provided in elementary schools
   (d) Compliance with ADA Title I Employment provisions
5. What causes rural communities to more likely experience difficulty with Americans with Disabilities Act compliance?
   (a) Many small towns in rural areas have limited financial resources.
   (b) There is plenty of knowledge about the Americans with Disabilities Act and how to comply with the Americans with Disabilities Act.
   (c) Most people do not want to accommodate an individual with a disability.
   (d) All of the above.
   (e) None of the above.
6. What is one potentially negative affect that ensuring compliance with the Americans with Disabilities Act has on rural communities?
   (a) Local governments may need to enact additional ordinances to enforce change, which is costly.
   (b) A complaint that requires enforcement makes the community take an adversarial role when working with members of the disability community.
   (c) The requirement of individuals and allies to advocate for ADA compliance.
   (d) All of the above.
   (e) None of the above.

7. Financial incentive plans may facilitate the ability and requirement of Americans with Disabilities Act provisions to be implemented by communities. What is one financial incentive?
   (a) Lower cost for changes made for accessibility in the community.
   (b) Rural communities do not get charged for making changes that increase compliance with ADA.
   (c) No taxes for businesses with accessible buildings.
   (d) Rebates, reimbursement, or loan forgiveness and low interest loans that can be utilized to comply with the ADA.
8. What are Area Development Districts (ADDs)?
   (a) Partnerships between states
   (b) Partnerships that make changes to legislation in the state
   (c) Partnerships that develop region-wide strategies, provide human services, develop a workforce, and administer various grants
   (d) Partnerships that are never affected by political factors
9. Which of the following was developed to provide a national network of technical assistance regarding the Americans with Disabilities Act?
   (a) The American Accommodation Network
   (b) The Accessibility Network
   (c) The Americans with Disabilities Act National Network
   (d) None of the above
10. Which of the following improve compliance with the ADA in rural areas?
   (a) Development of technical assistance resources
   (b) Financial incentives
   (c) Outreach to individuals with disabilities
   (d) All of the above
   (e) None of the above

Key

1. D
2. D
3. B
4. C
5. A
6. B
7. D
8. C
9. C
10. D

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Rural Forensic Vocational Rehabilitation Practice: Challenges and Opportunities for Rehabilitation Professionals

Ralph M. Crystal and Christopher Rymond

Overview

Forensic testimony has a long history that is traced to the late 1700s in which expert witness was used in case law in the case of *Republica* vs. *Ross*. At the various levels of appeals, the exchange that took place is suggested to have been new in forensics (Barros-Bailey, 2014). Over time the question of whether expert testimony could be useful was no longer the focus, but what kinds of questions and hypothetical scenarios could be presented. Eventually, forensic vocational expert testimony evolved into an examination of the components of work, work environments, and individual's capabilities to perform work and earn income.

Today, the forensic vocational expert's role is solidified across multiple jurisdiction ranging from determining damages in employment law to offering opinions on the liability of action when determining whether accommodations were reasonably offered (Barros-Bailey). The forensic rehabilitation expert has numerous tools that can be used to assist the courts in determining the impact of disability upon an individual and/or his or her surviving family members (International Association of Rehabilitation Professionals, IARP, 2016). Although the forensic vocational experts apply their skills in a variety of settings, they are to consider the context in which they provide opinions. That is, in rural settings, forensic experts must understand how to apply the particulars of rural circumstances in interpretation of evaluation and planning and rendering of opinion.

Rural forensic vocational rehabilitation practice has numerous challenges including cultural expectations, transportation, test administration, vocational recommendations, and planning. Individuals referred for forensic vocational services may not understand the reasons for the evaluation or even what is vocational rehabilitation. These individuals may be expecting to speak to a physician or a psychologist about their physical or mental problems and be unaware that the evaluation process involves aptitude and achievement testing. Individuals may travel long distances to attend vocational evaluations and be unaware of how long the evaluation process typically takes and often confuse a vocational evaluation with a psychological evaluation or a functional capacity evaluation.

Recommendations made by rehabilitation professionals for vocational rehabilitation services, education, vocational training, or return to work may conflict with an individual's view of their own academic, physical, mental, or work capabilities. If individuals are unable to return to

R.M. Crystal (✉)
University of Kentucky, EDSRC Department,
Lexington, KY, USA
e-mail: ralph.crystal@uky.edu

C. Rymond
Kynexia, Lexington, KY, USA

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their previous work or work which they value, they may find that the jobs for which they qualify conflict with their work values and temperaments. Jobs within an individual's vocational capabilities may be scarce or even unavailable in the area in which they reside, and recommendations by a vocational rehabilitation professional may have profound consequences upon an individual's lifestyle or even where they live. Being aware of these issues can help rehabilitation professionals provide objective assessments of an individual's work capabilities while also addressing an individual's strengths, deficits, and barriers to employment.

The field of forensic consists of specific terminology. A glossary of terms is provided to assist the reader in understanding the meaning of such terminology used throughout this chapter.

Learning Objectives

By the end of this chapter, the reader should be able to:

1. Understand the perspectives of rural residents who become involved in the forensic vocational rehabilitation process.
2. Recognize some of the economic, legal, social, and cultural factors rural residents face, which can be barriers to successful vocational rehabilitation and a return to work.
3. Develop a better understanding of the areas of practice of forensic vocational rehabilitation and how those services are affected by the unique challenges faced by individuals living in rural areas.

Introduction

A discussion of the unique challenges and opportunities for rural forensic vocational rehabilitation practice and ways practitioners address these challenges and opportunities are addressed in this chapter. The reality of rural residence, employment opportunities, current changes in employment, cultural and familial expectations, gender roles, and the impact of disability are discussed. This chapter should help the reader view the process of forensic rehabilitation from the perspective of the rural residents involved with forensic vocational rehabilitation services. The authors provide the reader with an understanding of how the vocational evaluation process and vocational recommendations can affect the emotional, physical, and economic lives of individuals with disabilities, their families, and their communities.

The forensic area of practice differs from public rehabilitation practice in so far as the individuals served are involved in some form of litigation, either fact finding such as administrative law or more adversarial such as civil litigation. The focus of the forensic rehabilitation professional can vary and may be to serve as a vocational expert, perform an evaluation, or provide vocational rehabilitation services. The question is not whether a person wants to do a job, would like doing a job, or can adapt and adjust to a job. The question is whether the person can do a job. Earnings and being able to perform past work, if the person is unable to return to such, are often secondary to the consideration of whether the person is able to perform any work in the competitive labor market, as jobs are typically found and performed. In employment law cases such as those filed under the Americans with Disabilities Act such concepts as "reasonable accommodations" and "essential job functions" must be considered.

Whereas public rehabilitation is typically based on meeting an eligibility standard, forensic or proprietary rehabilitation is based on entitlement. For example, a person is entitled to Social Security Disability based on paying into the system or meeting income requirements. An employee is entitled to worker compensation by virtue of being an employee. A person injured in an automobile accident is entitled to compensation based on being injured and insurance coverage.

In forensic rehabilitation, issues such as "order of selection" and severity of disability (with the exception of Social Security Disability) are not factors to consider with regard to whether a person will receive medical, monetary, and vocational rehabilitation services. However, in forensic practice, decisions regarding eligibility for benefits as well as the type and amount of benefit awarded may be made by judges and juries based on the results of vocational evaluations and recommendations made by rehabilitation professionals. Rehabilitation professionals should be aware of the potential effects of their conclusions and recommendations even as they strive to remain objective with regard to the assessments they perform and the recommendations they make.

Areas of Vocational Rehabilitation Forensic Practice

Rehabilitation practitioners engage with individuals with disabilities involved with claims or litigation, which involve disability and employment. There are two primary areas of law involved: administrative law and civil litigation. Social Security Disability and worker compensation are administrative systems that are designed to determine an individual's eligibility for benefits. Personal injury, employment discrimination, and wrongful death claims typically involve litigation or lawsuits brought about as the result of a tort or "a private or civil wrong or injury, other than breach of contract, for which the court will provide a remedy in the form of an action for damages" (Black's Law Dictionary, 2016). These matters are litigated in federal and civil courts.

Domestic relations cases typically involve divorce cases where there is a question regarding the ability of one or both spouses to work and earn income based upon their age, education, work history, and any physical or mental impairments. Domestic relations cases often answer similar questions regarding earnings capacity, work life, and employability that are addressed in personal injury and wrongful death claims.

Employment cases often involve wrongful termination or workplace discrimination claims. Vocational experts may be hired to testify about an individual's separation from employment and what affect that loss of employment might have on future earnings and employability. In these cases, vocational experts may be asked to evaluate whether an employee is eligible for protection under the Americans with Disabilities Act (ADA) or the Equal Employment Opportunity Commission (EEOC) based on the nature of any physical or mental impairments or the nature of the work.

It is important to understand the specific functions of the jobs and whether they are *essential functions* or *marginal functions* of the job. Additionally, a vocational expert may be asked to evaluate what accommodations might be available to help an individual perform the functions of a job and what those accommodations might cost an employer. The expert must consider what would be a *reasonable accommodation* and the rationale behind that determination.

Although the Americans with Disabilities Act is a national law, how the provisions of the ADA are applied may be different with different employers. For example, there can be two identical jobs; both may involve driving, but the act of driving is not an essential function of the job but a marginal function. The essential function is the work to be done when the individual arrives at the destination. In an urban area where a public transportation system exists, a reasonable accommodation would be to use that system. However, in a rural area where no public transportation exists, a reasonable accommodation would be to employ a driver or to reassign job functions. Nevertheless, a jury may determine that neither of these is "reasonable" and that rather than being a marginal job function driving is actually an essential job function.

Social Security Disability

In Social Security Disability, rehabilitation counselors are often involved as consultants, contracted by the government, and as "vocational experts." As a vocational expert, or VE, typically a rehabilitation counselor is responsible for reviewing exhibits pertaining to an individual's work history, listening to the claimant's testimony regarding their past work, and classifying that individual's past work based on the *Dictionary of Occupational Titles* (DOT) in terms of skill level and level of exertion. Vocational experts appear in person, by video teleconference, or by telephone for Social Security Disability hearing which includes an administrative law judge, the claimant, the claimant's representative (if they are represented), and a hearing reporter.

The VE then may be asked to provide opinion testimony about whether an individual might be able to return to any of the past work or alternate work based on a residual functional capacity (RFC). This residual functional capacity is composed of limitations described by the claimant or contained in the medical records, which the judge or representative feels describe the claimant's level of physical and mental functioning. The VE will offer his or her opinion on whether an individual with the limitations described by the judge or representative could return to any of the past work (as actually performed by the claimant or as typically performed in the economy) or alternate work. The VE may also be asked about what, if any, *transferable skills* an individual may have acquired from past work which might transfer to other jobs in the economy.

The definition of disability in Social Security is whether the individual has a physical and/or mental impairment that prevents the individual from being able to perform a significant number of jobs in the national economy for a person of at least 12 months or will result in death. The determination of significance is made by the administrative law judge, who presides over matters pertaining to the Social Security law. Since Social Security is a national program, the ability to get to a job, the availability of jobs in a particular region, or whether the person will actually be hired is not considered. The question for the VE is whether jobs existing in different occupational areas exist throughout the national economy based on factors presented by the judge. As an administrative process unlike a civil case, disability hearings are closed to the public. In civil litigation the public can attend although witnesses are sequestered.

A VE does not determine what a claimant's residual functional capacity is, but rather responds to questions posed about a "hypothetical" individual's ability to perform work based on specific limitations. The vocational expert should listen carefully to a claimant's testimony regarding how the past employment was performed including the training it took to perform that work as well as the physical requirements of that work. Claimants may have performed jobs which were unique or classified by multiple job titles by the DOT or not well described by the DOT description. Since judges and representative may ask an expert about aspects of claimant testimony, vocational experts should listen carefully to the claimant's description of their impairments and how those impairments affect their ability to function.

The Social Security Disability process is intended to be an administrative process and non-adversarial. However, when claimants are represented by attorneys or non-attorney representatives, the questioning of a vocational expert can become contentious. A claimant representative or even an administrative law judge might subject a vocational expert to many specific questions regarding the classification of past employment or about other unskilled jobs which they might cite as available in the economy based on the residual functional capacity. Often these questions will regard the numbers of jobs in the economy and the sources of an expert's information. Experts rely on their education, training, and experience in the field of vocational rehabilitation on which to base opinions; however, opinions regarding the numbers of jobs in the economy and the way jobs are performed should also be based on quantitative data and current peer-reviewed research whenever possible.

In Social Security Disability cases, rehabilitation professionals will often encounter individuals from rural areas with past work experience in skilled and semiskilled work learned with little formal training or on-the-job training and experience. These jobs are often in the mining, construction, agriculture, transportation, and manufacturing industries. In determining the skill level and any transferable skills from such work, a vocational expert should consider what specific tasks an individual was performing, what licenses and certifications a claimant may have, and the length of time an individual performs a particular type of work.

If available, an examination of the Social Security earnings record may reveal the tenure of a particular job and the average hourly or weekly earnings. These data can often provide insight into the skill level of a particular job by revealing the value of that employee to the employer and in the economy in general. A vocational expert can compare the earnings of a claimant to earnings of similar workers in the areas to help determine the relative skill level of that employment.

Rural workers will often have self-employment earnings for contract labor, agricultural labor, or service labor such as mechanic work, farm labor, and housekeeping services. The share of self-employed rural workers has been growing over the last 30 years, peaking in 2007 prior to the Great Recession (Goetz, 2008; Hertz, 2016). Vocational experts should understand that reported self-employment income may be lower than similar income paid through an employer (Spizman, 2002). Additionally, work through self-employment often requires an individual to generate their own business, keep track of expenses, give estimates, and bid jobs. These aspects of self-employment indicate a level of skill and insight not typical of low-skilled work. For these reasons, a vocational expert should take note of the specific tasks performed by a worker as well as the level and consistency of the earnings generated.

Several factors need to be kept in mind with regard to Social Security Disability. It is a national program. The same standard for disability is applied for claimants in rural and urban and suburban areas. The criteria is not whether the individual can or cannot perform his or her past work or work that exists just in the person's local regional economy but can the person perform work that exists in significant numbers (determined by the judge) in the national economy. Also, getting to a job is not considered, just whether the individual can perform the work.

Worker Compensation

Worker compensation grew out of the industrial revolution in the first past of the twentieth century when individuals were being injured in industrial accidents. At the time the common law concept of the inherent danger of work and the acceptance by the worker of the dangers and hazards in the workplace was in effect. Thus, if a worker were injured, he/she would need to prove negligence in a civil court. This was often a difficult standard to meet and prove and would be a costly and a time-consuming civil litigation process.

Worker compensation thus became a compromise between workers and employers, whereby the worker gave up the right to sue (often for large amounts if successful) for immediate medical and monetary benefits. The amount of income benefits is typically capped in worker compensation and based on state wage rates related to the general state working population or based on the industry the individual was engaged in. Also, medical benefits including treatments and medications were tied to the effect of the injury and not any other impairments the individual might have.

In civil litigation, an injured person can be compensated for pain and suffering, punitive damages, as well as loss of capacity to earn money. Pain and suffering can include quantifying physical pain and psychological damage resulting from the injury such as post-traumatic stress disorder, flashbacks, and panic attacks. Punitive damages can be a punishment for an employer knowing of a safety hazard or violation but not doing anything about it. Lost wages can be for the actual amount of lost income. In worker compensation, there are no damages awarded for pain and suffering, no punitive damages are awarded to the claimant, and wages are capped to state or industry levels. If there is a safety violation, the employer may be fined, but the injured person does not receive this as compensation.

Worker compensation claim often involves vocational rehabilitation counselors working as consultants and evaluating an individual in terms of their capacity to return to work as a part of an administrative process. Worker compensation programs are state legislature and mandated administered insurance into which employers pay premium in order to insure themselves against work injuries incurred by their employees.

Each state administers their worker compensation differently, and the standards, which determine an individual's eligibility for benefits, may be different between states. As worker compensation claims are filed when a worker is injured on the job, the claimants in these actions all have some type of work history and were working at the time they were injured.

In a worker's compensation evaluation, a vocational rehabilitation counselor will typically conduct a formal vocational evaluation including a structured interview and vocational testing. The structured interview should be designed to collect information on the claimant's background including age, education, past work, areas of residence, disability status, and subjective reports of their physical and mental functioning. Vocational testing will typically include aptitude and achievement testing as well as interest inventories, personality tests, and manual dexterity tests.

The vocational expert will also review and abstract reports concerning specific levels of physical and mental functioning from medical records. This will include records from physicians, surgeons, physical therapists, psychiatrists, psychologists, counselors, and other vocational experts. The specific type of records to be reviewed is mandated by the nature of the claim and the state law.

As in many cases, records and reports reviewed might present inconsistent opinions as to the physical and mental functioning of the claimant. The vocational expert should avoid making determinations as to the credibility or weight afforded physical or mental assessments. Instead the vocational expert should present a range of opinions consistent with the range of functioning described in the records reviewed. Similarly, a claimant may view their own physical or mental functioning differently than the way it is described in the physical and mental health records. A claimant's opinion regarding their level of functioning should always be documented in a vocational evaluation report; however, these opinions are often regarded as subjective compared with the more objective opinions of qualified physical and mental health providers.

Individuals involved in worker's compensation claims may have a wide variety of physical and mental impairments as a result of their injuries. Often in such cases, an individual will be unable to return to the type of work they performed as the time they were injured. This is often true of individuals involved in medium or heavy construction, agricultural, mining, and transportation jobs. If an individual is unable to return to their past work, the vocational expert should conduct an assessment of what alternative work might be available that the individual would be capable of performing.

Recommendations for alternate work include specific jobs, which the claimant is currently able to perform given their level of physical and mental functioning. Recommendations should also include jobs for which the claimant has transferable skills. Additionally, if vocational testing indicates that the claimant is capable of retraining for other work, recommendations should be made for retraining and return to work options. This could include retraining for alternate work through a 6-month to 1-year certificate or diploma program, 2-year technical or associate degree training, or on-the-job training and experience.

Retraining and return to work recommendations should correspond with requirements and obligations described in the worker compensation regulations of the state or commonwealth in which the claimant is covered. The concept in worker compensation is similar to other forms of insurance. That is return the individual physically, mentally, and economically to the prior level of functioning. This is not always possible, particularly when there is a permanent injury, but through retraining the individual is assisted to be able to at least function economically at a prior or similar level of functioning.

Because vocational evaluations for worker's compensation claims often involve vocational testing, the vocational rehabilitation professional will often encounter issues regarding motivation, understanding, frustration, and pain tolerance. Many rural workers evaluated for worker's compensation claims may have little formal education and training. While the educational attainment of people living in rural areas has increased over time, it is still well below that of residents of metropolitan areas (Marré, 2016). Some individuals may have cognitive problems, learning disabilities, or difficulty with reading, writing, and arithmetic, which are a source of significant shame. Older workers with little formal education will likely have not been in a school setting for many years and be unused to the standardized tests typical in vocational testing. For individuals with pain issues, the length of time typically required for vocational testing may cause an increase in pain and discomfort throughout the evaluation.

For some claimants, the worker's compensation process may have been difficult and protracted, and they may feel they have had to "fight" for the medical treatment and financial benefits they deserve. These claimants may be wary of the vocational evaluation process and believe that it is designed to thwart their attempts to receive treatment or benefits. If a rehabilitation professional is retained by an insurance firm or an attorney representing an insurance firm, the evaluator may be viewed as an agent of those who would seek to deny them treatment or benefits.

A well-developed contract of rights and responsibilities between the evaluator and claimant should be developed to explain the purpose, nature, and scope of the vocational evaluation process. By obtaining a signed agreement regarding rights and responsibilities, the claimant will understand that they and the evaluator are under similar obligations to provide a good effort on testing and honest answers to questions posed. Such a contract establishes that the claimant entered into the vocational evaluation process with an understanding of the purpose and scope of the evaluation.

A vocational rehabilitation counselor administering vocational tests should be aware that claimants may be intimidated by the vocational testing and evaluation process. A good effort from the claimant on vocational tests administered is essential to obtaining a valid and reliable measure of that individual's levels of aptitude and achievement as well as areas of interest and personality profile. The vocational evaluator should strive to create a friendly, open, and inviting evaluation environment.

Questions regarding the evaluation process, vocational testing, reporting of results, and recommendations should be answered in a straightforward manner. Claimants who become discouraged during the testing process should be encouraged with regard to effort. Breaks should be offered frequently, and accommodations in terms of time, scheduling, and ergonomics (such as the ability to alternate positions during testing or the provision of magnifying glasses for written material) should be made whenever possible.

Vocational testing results may underrepresent the actual academic, intellectual, and aptitudes of the individual. When appearing for the vocational evaluation, the individual may not be aware of the vocational testing and not be prepared for the testing or length of the evaluation. In addition, the individual may have been out of an academic environment for many years and not perform as well as might be expected. For example, most people use math and read at a fifth or sixth grade level for daily activities, and although they may have a high school diploma, many do not test out at a high school level if functioning on a job at that level has not been required.

While the worker compensation process is typically administrative in nature and designed to be non-adversarial, the insurance carrier and claimant are usually represented by legal counsel. Because of the nature of the worker's compensation process, there may be disputes between the claimant and the worker compensation provider as to the level of disability of the claimant, treatment required, and whether the claimant is capable of returning to past work or any work at all.

A vocational rehabilitation evaluator may be questioned in a deposition regarding the conclusions of their vocational evaluation and the basis for those conclusions. The vocational evaluator may be asked to review and critique reports from other vocational evaluators who offer differing opinions. Because the opinions of a vocational evaluator can have very specific economic consequences for a particular case, these opinions and their basis will be scrutinized in detail by an attorney and other professionals.

The vocational evaluator is best served by offering unbiased opinions based on the most current and reliable evidence available. If more information about a claimant's background, past work, or medical treatment is needed, it should be requested. Diligence in collecting accurate information and assuring valid and reliable results on vocational testing establishes a solid foundation on which their vocational opinions are offered.

As state legislated and administrated programs, the nature of the program and the benefits available are often structured based on the economic composition of the state. Differences in worker compensation systems are often based on whether a state is a rural, an agrarian, or a more industrial state. Each state has its own worker compensation law, and consequently the medical, vocational rehabilitation, retraining, and return to work benefits vary from state to state. Worker's compensation laws in a state are subject to being changed whenever the legislature meets.

Conflicts can arise when a state bases an award of benefits on a strictly "impairment of disability" model or an "occupational disability" model. In an impairment model, the judge determines the level of benefits based on the impairment of disability he or she has decided exists.

In an occupational disability model, the judge considers factors such as age, education, past work, and geographic location. In the impairment model, everyone with the same level of impairment receives the same level of benefits. Impairment is based on objective guidelines which award a percentage of disability to each body part and also a percentage for surgery, and in the case of mental impairments, the disability rating is based on the *Diagnostic and Statistical Manual of the American the Psychiatric Association* (2013).

In the occupational disability model, the judge can consider where the person resides in awarding benefits. Thus, in rural areas where access to employment may be limited, a person may receive a greater level of benefits than an individual with the same level of impairment as a person in an urban area. In either a strictly impairment or occupational disability model, there can be injustices. Thus, hybrid models in which a judge has the discretion to consider not just the impairment but the person's age, education, past work, and opportunities for retraining and employment are the most equitable. This is where the rehabilitation professional aids the judge with conducting vocational evaluations and offering vocational and retraining opinions.

Personal Injury, Wrongful Death, and Childhood Claims

Personal injury, wrongful death, and childhood claims typically involve civil litigation including a tort. In these claims, a vocational evaluator is often asked to assess a loss of employability, earnings capacity, and work life due to an injury, disability, or death. Claims of personal injury or wrongful death involving minor children will have a vocational evaluator assess a loss involving a minor child; however, without an established earnings capacity or career path, the estimate of future earnings of minor child is more speculative than that of an adult by their very nature.

Because these cases are adversarial in nature, there can be a high degree of scrutiny of a vocational expert's opinions and the basis for those opinions. Very often there will be a report from another vocational or economic expert expressing opinions, which may differ with or critique the opinions of the vocational expert. A vocational expert will likely have to testify in depositions or trials about their opinions and the basis for those opinions. Because these cases can involve juries who may not have experience with vocational rehabilitation services, the conclusions and opinions provided for these cases must be expressed in a way that the average person can understand.

In personal injury, wrongful death, and childhood claims, the evaluation process is very similar to that as described for worker's compensation claims. Claimants will often be given aptitude and achievement tests, personality surveys, and interest inventories as described in the prior section on worker compensation. Similar to other types of claims, there are concerns with regard to effort, reliability, and validity of the testing process.

Claimants in personal injury, wrongful death, and childhood claims will also have similar concerns about fairness and the evaluation process as described with worker's compensation claimants. Claimants may have emotional reactions to the effects of an injury or the death of a loved one. A vocational expert should be aware that there may be issues a claimant may need to express in order to feel as though their concerns are being heard which may not be directly relevant to the questions being addressed by their report.

When evaluating the loss of earnings capacity, work life expectancy, and employability for rural residents, the economic context and physical nature of current and past employment are important to producing an accurate measure of lost earnings capacity. For rural workers engaged in physically demanding mining, construction, agriculture, transportation, and manufacturing work, traditional estimates of earnings capacity and work life may overestimate or underestimate the value of future lost wages. Future lost wages can be based on the inability to perform the usual and customary work the individual did previously. For example, if the person did a manual labor job operating heavy equipment and earning $25.00 an hour but can now only do a job such as working as a cashier and being paid $10.00 per hour that would result in vocational economic loss of $15.00 an hour.

Workers engaged in physically demanding work activities, especially those with high rates of injury, will often have shorter work lives than individuals involved in less physically demanding or dangerous jobs (Rho, 2010; Tang, Choi, & Goode, 2013). Additionally, physically demanding and dangerous jobs often pay more than other work, especially in rural areas. By using a work life estimate which does not account for the likelihood of a shorter period of work in a physically demanding or dangerous job, a vocational expert will overestimate a worker's lost earnings. When estimating the work life of individuals employed in physically demanding or dangerous work, vocational experts should use all available information including research or industry data specific to the worker's employment.

A worker with little formal education engaging in physically demanding work in an area of economic decline may have a limited work life in that occupation even without a physical or mental limitation (Rho, 2010; Tang et al., 2013). However, self-employed workers who reinvest earnings into their business may actually have an earnings capacity far higher than that which they demonstrate through their earnings records or tax returns. In each case a vocational evaluator should look at the experience of similar workers in the local and regional economy and model any work life or earnings capacity estimates accordingly.

Labor Market Changes Affecting Rural Residents of the United States

Residents of many rural areas of the United States have seen a loss of economic opportunity in the last few decades. This has been largely the result of two major factors: the urbanization of the US population and the polarization of the labor market in terms of the skill and wages of jobs (Holzer, 2015; Kusmin, 2016). Rural areas are experiencing declining populations; at the same time, employment and wages for traditionally middle- and high-paying jobs in rural areas are also in decline. The majority of new jobs in rural areas are low paid and low skill, which are typically replacing more skilled jobs with higher earnings (Kusmin, 2016).

Since the 1980s, job growth has been increasing for both the top and the bottom of wage distributions, and the numbers of jobs with middle-class wages have been declining (Holzer, 2015). While there is growth in the numbers of low-skilled jobs, these jobs are often at the lowest levels of the income distribution. Jobs with the highest wages are growing as well; however, these jobs tend to require higher levels of education, skill, and experience. The period of recession in the United States between 2007 and 2013 (Holzer, 2015) accelerated this trend with losses in well-paid jobs in the mining, production, clerical, and construction industries. Additionally, since 2000 job growth in general has been concentrated greater in urban areas, increasing the problem for rural residents (Kusmin, 2016).

Middle- and high-income jobs which can be performed with little formal training or on-the-job training and experience are disappearing. These jobs are being replaced by low-paid, low-skilled jobs and high-paid, high-skilled jobs. The jobs that are the most accessible are increasingly the lowest paid. This creates economic barriers especially for middle aged and older workers who need to transition to alternate work due to health problems or disability.

In a forensic vocational rehabilitation setting, practitioners will often encounter workers who are faced with transitioning from physically demanding jobs to less physically demanding jobs. Unfortunately, these less physically demanding jobs for which individuals will qualify will often pay less than the individuals' past employment. Alternate work may also conflict with an individual's work interests and temperaments significantly reducing an individual's incentive to return to the workforce. Consider the case example below of a hypothetical worker, Mr. Joe Smith:

> Joe Smith, who was working as a welder and heavy equipment repairer at a surface mine or in construction, a job requiring heavy lifting and extensive postural activities as well as significant standing, walking, and working around hazards. Joe is in his early 40's and has lived and worked in the same rural community most of his life. While he has migrated regionally for work in the past, in recent years he and his family have settled in a rural area of the state near his parent's residence where he grew up. Joe did not complete high school however he completed a GED and learned to weld and perform maintenance and repairs on heavy equipment through on the job training and experience. Joe enjoyed his job and earned a wage of $30 per hour plus benefits and overtime, a very comfortable income in the rural area where he resides.
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> Joe is injured when a piece of equipment shifts during a repair and crushes his right leg. Joe survives the injury however his leg requires extensive surgical repair and he develops a pain disorder in the right leg. After almost two years of medical treatment Joe is released by his doctors and referred to a functional capacity evaluation to determine his physical work capabilities and a psychological evaluation to determine how the pain and the trauma of the injury have affected his mental capabilities.
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> It is determined by a functional capacity evaluation that Joe will be able to perform light work in the future lifting up to 20 pounds occasionally, however he will be limited in his ability to stand and walk to approximately 30 minutes at a time and will need to periodically alternate positions. Joe's physicians concur with the results of the functional capacity evaluation and recommend that Joe be released to return to work at the sedentary or light level of exertion. A psychological evaluation finds that Joe has depression and a pain disorder due the work injury but the psychologist does not recommend specific mental work limitations for him. Joe is treated by his family doctor for pain and depression however there are no mental restrictions placed on his ability to work.
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> Despite the results of the functional capacity evaluation and the recommendations of his physicians, Joe experiences pain and feelings of depression on a daily basis due to the injury and the loss of his job. Joe considers himself to be completely disabled because of the pain he experiences and his physical limitations will prevent him from returning to his past work which paid well and he enjoyed. When he is determined to be at 'maximum medical improvement' (he is basically improved as much as possible from the injury) for his injuries Joe is referred to a vocational evaluation by his former employer's workers' compensation insurance carrier to determine what work, if any, he might be capable of performing.
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> Joe travels over two hours from his rural home to a nearby city where the evaluation will occur. Because of difficulty with driving long distances due to the right leg pain Joe has his wife drive him to the evaluation. When Joe and his wife arrive for the evaluation they are uncertain of what to expect. Joe believes he will meet with a physician to discuss his medical problems and is surprised to learn what a 'vocational evaluation' is. Joe is somewhat frustrated to learn that the vocational evaluation will take upwards of six hours and he will be expected to complete a range of academic and achievement testing. Inwardly Joe considers himself to be disabled from working and feels that this evaluation is a means for the insurance company to deny him benefits to which he is entitled.
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> Despite his reservations Joe is cooperative and participates in an interview and completes the vocational testing to the best of his ability, knowing that if he does not the judge might dismiss his case for not cooperating. Joe explains his physical and mental difficulties to the rehabilitation counselor conducting the evaluation and he also expresses his frustration with his experience with the worker's compensation process. Joe feels that he has been treated poorly and that he has had to fight the worker's compensation carrier for treatment and benefits he deserves. He feels that little consideration has been paid to the devastating nature of his injury and the effect it has had on his

> life and the lives of his family. While Joe understands the necessity of a vocational evaluation he does not view himself capable of returning to his past or other work, however he acknowledges that he does not know if there is work he would be able to perform given his limitations.
>
> Joe performs well on the academic and achievement tests administered, scoring in the average range on intellectual assessments, with achievement testing placing him in the range of an 8th to 10th grade equivalent in arithmetic, reading, and spelling. The results of the vocational testing indicate that he would be capable of formal training for other work and with a GED he is capable of enrolling in a technical or community college program. Interest assessments indicate that Joe has a preference for manual labor activities performed with little interaction with others or monitoring from supervisors. Joe reports to the rehabilitation counselor that while he has thought of returning to school but does not feel as though he would do well in school because he has a difficult time in school previously and he feels that the pain and physical limitations he currently experiences would further limit him in a formal learning environment.

After reviewing the results of the vocational testing and the opinions of the medical providers (limiting him to sedentary or limited light work), the rehabilitation counselor concludes that Joe is not capable of returning to his past work as a welder and equipment repairer and is also not capable of returning to work with which he might be able to utilize transferable welding, maintenance, and repair skills from his past work. However, the rehabilitation counselor does find that Joe is capable of a range of unskilled, entry-level work without retraining such as customer service, clerical, sales, clerk, nonhazardous security, and cashier work. It is also concluded that Joe benefits from formal retraining for other works existing at a sedentary and light level of exertion through short-term formal training through a technical or community college program.

A labor market survey of existing jobs in a particular region is conducted by the rehabilitation counselor which indicates that there are a range of customer service and cashier jobs available within approximately 25 miles of Joe's residence which he would be capable of performing. There are a limited number of these jobs in the area where Joe currently resides however and many more such positions in urban settings much farther from his residence. Also when applying for these jobs, Joe would be competing against other individuals without disabilities, who may be younger and already have skills such as operating a cash register, dealing with customer complaints, or handling money which Joe would need to learn.

The jobs which Joe is capable of entering without training pay between $7.25 (minimum wage) to $10.00 per hour. With formal training and education, Joe could qualify for jobs paying in the range of $15.00–$20.00 per hour; however, this would require 6 months to 2 years of academic work from Joe which he would likely find to be difficult for him. In either case Joe would earn substantially less than he did with his prior work as a welder and heavy equipment repairer. Additionally, the work now available to Joe would require much more interaction with coworkers, supervisors, and the public than Joe is used to or would prefer. Joe often find extensive interaction with others to be stressful which is worse since his injury as he feels embarrassed by his physical limitations.

As someone who was not comfortable in an academic or social environment before being injured, Joe is now more apprehensive about such settings since his injury. Since Joe lives out in a rural area, he would need to drive approximately 30 miles each way to and from work driving about an hour and a half every day on narrow country roads. With pain in his right leg limiting his ability to drive, this commute would also be difficult for Joe.

Despite the recommendations from the rehabilitation counselor, Joe still considers himself completely disabled from work. Joe attends another vocational evaluation arranged by his attorney, and this evaluation finds Joe to be completely disabled from any work which might be available to him based on his physical limitations as reported by medical experts, lack of education and job skills, as well as the pain and physical limitations which Joe reports.

After reviewing the information in the case of Joe Smith, answer the following questions:

1. Do you consider Joe to be disabled?
2. What other factors might affect Joe's feelings about his ability to work?
3. What else could be done to help Joe return to work?
4. What do you think are the best options for Joe?

Rural workers face declines in employment and declines in pay in the jobs that are available to them. Declines in employment in the agricultural, construction, production, and mineral extraction sectors have led to overall declines in rural economies. Skilled jobs and jobs in the expanding health, managerial, and service sectors are increasingly found in urban areas. Overall rural populations in the United States have been steadily declining, further reducing economic opportunities in these areas (Hertz, 2016).

Declines in traditionally middle-wage jobs in the construction, production, and clerical sectors of the economy have led to declines in economic opportunity for low- and middle-skilled workers in rural areas. Regionally, employment growth in coal, oil, and gas production has shifted from areas of Appalachia to the Plains States and areas in the western United States. Jobs in the transportation sector such as truck driving remained relatively stable during the Great Recession; however, these jobs are often physically demanding (Kusmin, 2016) (see Chap. 1 for more information on occupational outlook in rural areas).

Does an injured person such as Joe have an obligation to mitigate his vocational economic damages through retraining and returning to work? Does an injured person such as Joe have an obligation to relocate to where a job he can do exists? Should Joe receive more monetary compensation because jobs do not exist where he resides than a person in an urban who can return to alternate work?

Barriers to a Rural to Urban Transition

Currently the growth of the labor market and employment opportunity is increasing in urban areas and decreasing in rural areas. Trends in employment and demographics indicate that individuals in rural communities seeking alternate employment would be best served by moving to urban areas. However, rural residents are often reluctant to move away from areas where they grew up and have an established support network as well as family and community relationships. Rehabilitation professionals will often make commendations for retraining and return to work which may conflict with an individual's desire to remain in the area in which they live.

Younger individuals are more likely to leave rural areas for educational and employment opportunities in urban areas (Glasgow & Brown, 2012). However, even younger workers, especially those with disabilities, may not view themselves as capable of leaving their support systems found in rural areas. Family, friends, community, and church are often central to an individual's identity, and the loss of these valued social supports is understandably undesirable for many individuals. Often rural residents view their area of residence itself as a part of their identity which would be lost if they moved into a city. Recreational activities, which they might value such as hunting, fishing, riding four wheelers, and riding horses, may not be accessible in urban areas. A significant loss of social support may be particularly difficult for individuals who are also experiencing significant economic changes in their lives (von Reichert, Cromartie, & Arthun, 2014).

The economic cost of moving to an urban area, even for a specific job, also presents a barrier for rural residents. Rural residents may reside in houses or on property, which is paid for or was left to them by their family. Support networks including family, friends, community, and church while also socially important often also serve as financial support in times of need for food, housing, or even direct financial assistance. Moving away from these social and financial supports may seem difficult or even impossible to some individuals, especially for older workers who may not generate long-term financial returns from relocation. While some living expenses (such as the cost of food and energy) and transportation expenses (due to decreased travel distances or use of public transportation) may be the same or even lower in urban areas, the cost of housing may be far greater depending on the area.

As younger workers seek to find education and employment opportunities in urban setting, their parents and older family members may discourage them from seeking these opportunities. This is often the case for young adults with disabilities. Parents often see themselves as responsible for their adult children, especially children who have disabilities. Parents or other adults may view these younger individuals as incapable of functioning independently, especially in an urban environment, which they themselves may view as unfamiliar, fast paced, and challenging.

In some cases, parents or guardians may encourage young adults to stay at or near home out of fear of losing the social and economic support of their younger relatives. This fear is not unfounded as rural areas have been experiencing a continual decline in population over the last few decades. The loss of jobs and the loss of young workers has led to a downward economic spiral of a decreasing tax base and decreasing local economy (Shah, 2014). Young workers faced with the prospect of leaving rural areas with social support may have been taught to view urban living or even their own social and financial independence as less desirable or unattainable. Young adults with intellectual disabilities may be encouraged by their parents to pursue Social Security Disability instead of employment as this might appear to be a more secure path for economic stability.

A vocational rehabilitation practitioner advising young adults in rural areas may find little family or social support for plans which encourage a young adult to move to an urban area to avail themselves of education or employment opportunities (Lindsay, McDougall, Menna-Dack, Sanford, & Adams, 2015). Many young adults in this situation find themselves faced with choices, which could anger or upset their immediate family. In some cases, individuals receiving childhood Social Security benefits may have actually been providing financial support to their family even as children. Parents faced with the removal of this support may undermine their children's economic and social independence in an effort to preserve a feeling of economic security.

Transportation

Physical distance and transportation are often significant barriers to individuals accessing the work available within rural areas. Rural areas typically have little or no access to public transportation requiring individuals to obtain access to their own private vehicle or share a ride with others in the community (see Chap. 3 for further discussion on transportation).

In the transition from a higher-paying job to a lower-paying job, the cost of maintaining, insuring, and fueling a private vehicle can be a significant barrier for individuals. This is especially true for individuals who may have some difficulty with driving. For individuals with disabilities, even a 30 mile drive along unlit two lane roads can pose a barrier. For individuals who are unable to afford to maintain a vehicle or unable to maintain a driver's license, this may be an insurmountable barrier.

Individuals with a disability living in a rural area may face many barriers to employment such as limited financial resources, transportation, and access to employment which are not considered for the award of Social Security, worker's compensation, or personal injury benefits. A rehabilitation professional should be aware of these barriers for rural residents and acknowledge their existence when considering what jobs are available to an individual. However, in forensic vocational rehabilitation, the standards for disability and eligibility for federal or state benefits are usually applied to individuals equally with little regard to the specific area in which an individual resides. Rehabilitation professionals should make recommendations which help consumers overcome barriers to employment and return to work in areas where they are most likely to achieve vocational success.

Gender Roles and Personal Identity

Rural residents, especially those of middle age and older, are often employed in occupations which conform to traditional gender roles. Men will often work in mining, construction, agriculture, transportation, and manufacturing occupations, and women will often work in health care, clerical, education, and service occupations. Males, especially those in high-paying or locally important jobs and industries, will often ascribe a significant part of their personal identity to the occupation they perform or performed prior to being injured.

Males residing in rural areas and employed in traditionally male-dominated occupations may view themselves as the “breadwinner” or the head of the household and may have difficulty adapting to a change in this role. Inflexible expectations with regard to gender roles, occupation, personal identity, and earnings can present a barrier for individuals who need to transition from one occupation or industry to another. In some cases, individuals may view the role of an unemployed person with a disability as more acceptable than performing work which threatens their personal identity or which they simply do not value.

When workers are put in a position where a full-time job will pay them little more or even less than disability payments, they are left with a stark economic choice: to work for less or become disabled. This choice is often coupled with a worker’s own identity and work preferences. An individual who identifies as a construction worker, welder, equipment operator, or truck driver making a middle-class income must overcome a loss of income and identity to transition into lower-paid service sector work such as a cashier, fast-food worker, warehouse worker, or low-skilled production worker.

Often individuals in skilled trades, mining, agriculture, manufacturing, construction, and transportation jobs prefer work with little social contact and are adverse to positions which require a high degree of social or public interaction. On occasion individuals may have developed habits of personal appearance and grooming such as wearing long beards and a causal style of dress, which they may be unwilling to change for a new job.

The Impact of Substance Abuse, Dependence, and Drug Culture

Rural areas have been disproportionally affected by a rise in substance abuse and dependence. Some of this has been caused by a high number of opioid pain prescriptions in rural areas often for individuals working in physically demanding jobs, which can cause both acute and degenerative injuries. Over time a high concentration of individuals dependent on opioid pain medication has developed in many areas such as Appalachia. High concentrations of individuals dependent on opioid pain medication have caused the development of a drug culture, which had not traditionally been associated with rural areas.

Involvement in the drug culture causes many problems for individuals including poor employment outcomes, legal problems, and adverse health consequences. As opioid pain medication has become more regulated, the use of black market heroin has increased. Involvement in drug culture often leads individuals to sell drugs or commit other crimes such as prostitution or theft to support their habit. Individuals residing in rural areas will often turn to marijuana cultivation or manufacturing methamphetamines to support themselves and their drug habit.

Substance abuse and dependence can become a significant part of individuals’ lives involving friends, family, and even coworkers. Individuals often spend significant amounts of time and money to acquire and use drugs and alcohol. Individuals who live in households with others who are involved with drugs or alcohol may have difficulty escaping a cycle of substance abuse and dependence. This can be especially problematic in rural areas with small populations and tight-knit social networks where there may be few options for housing and individuals often live with extended family. An individual attempting to abstain from drugs or alcohol may be more likely to relapse if they live or regularly associate with others involved with drugs or alcohol.

Abuse and dependence of drugs and alcohol can have a lasting negative effect on earnings and employment of workers (MacDonald & Pudney, 2000). Drug and alcohol dependence can result in lost work hours, work site injuries, and jobs loss (Lehman & Simpson, 1992; Mangione et al., 1999). Legal problems as a result of drug and alcohol abuse and dependence can prevent individuals from obtaining work in the future. In rural areas with few employers, an individual's problems with drugs and alcohol or legal trouble may often be well known, and that reputation can have a negative effect on employability (Compton, Gfroerer, Conway, & Finger, 2014; French, Roebuck, & Alexandre, 2001; Huang, Evans, Hara, Weiss, & Hser, 2011).

Employers in many areas of the country have a difficult time finding workers who can pass a pre-employment drug screen (Calmes, 2015). Areas with high rates of substance abuse and dependence often have a difficult time attracting new employers due to the difficulty with finding drug-free employees as well as higher worker compensation insurance rates, exacerbating the problem of obtaining employment in rural areas.

Treatment for problems with drugs and alcohol may be limited for residents of rural areas (Pullen & Oser, 2014). Often inpatient drug and alcohol rehabilitation will not be available locally and must be obtained in urban centers. Similarly, chemical detoxification or maintenance programs such as Suboxone and methadone treatment are also not available locally and must be obtained elsewhere. For some rural residents, local treatment options might be nonexistent or limited to self-help programs such as Alcoholics Anonymous or Narcotics Anonymous meetings. The time and money required for travel to and from drug or alcohol treatment are another burden rural residence with these problems must face when seeking to obtain or maintain employment (see Chap. 28 for discussion on substance abuse).

In addition to reducing employability, problems with drug and alcohol abuse and dependence can complicate an individual's claim for government benefits or through personal injury litigation. An individual may be found ineligible for Social Security Disability benefits or worker's compensation benefits if drug or alcohol problems are found to be a contributing factor to an individual's disability or work injury, the absence of which would not render the person as being disabled. With personal injury or wrongful death litigation, a preexisting drug, alcohol, or legal problems could be determined to have a significant negative effect on an individual's earnings capacity and work life expectancy. Reduced estimates of work life and earnings capacity would typically reduce the overall value of a monetary claim based on these factors.

Access to Education

For most workers in the United States, higher education and technical training offer the best chance for an individual to improve their employability and earnings capacity. However, residents of rural areas may have less access to educational opportunities than urban residents (Marré, 2016). Colleges, universities, and technical programs are often located in more centralized or urban areas requiring rural residents to travel or move away from their support network. Online and distance learning programs have increased opportunities for rural residents and individuals with disabilities; however, areas of study may be limited in these programs. Additionally, students who would like more individualized instruction or who may need additional assistance or accommodations with schoolwork may be limited in what help they can receive via online or distance learning programs.

Public education in rural areas may be limited by low property tax values and limited school choice. An individual living in a particular area may only have the option of one local high school. The quality of a public high school education in the United States can vary widely depending on the school district or the individual school. Families residing in urban areas may be able to change schools for their child by moving to another district within a city. Rural residents may be less willing or less able to relocate or move between school districts to improve educational opportunities for themselves or their children.

Urban areas often provide individuals with educational and cultural opportunities, which are unavailable to rural residents. Museums, theaters, and cultural centers, which are often located in urban areas, provide access to language and arts classes as well as lectures, performances, and artistic and historical exhibits. Rural residents often must have access to leisure time and transportation to enjoy these opportunities.

Many individuals withdrew from school or did not take school seriously when jobs were plentiful and high paying. The question raised was, "why should I attend school when I can make more money working in a physically demanding job than I can make by staying in school." Thus, the perceived value of education has led to lower levels of school completion and development of a skilled workforce in rural areas. Rural workers are not less intelligent than their urban counterparts, just less educated. However, as jobs that are high paying and not requiring extensive education to perform have declined, there has been a rise in poverty levels and drug usage and dependence.

Continued education offers the best opportunity for most individuals to improve their employability or earnings capacity. However, work values common in rural areas are often inconsistent with the development of vocational skills, which are the most beneficial in the economy, which is increasingly polarized by skill and urbanized by convenience. Rural workers employed in mining, construction, agriculture, transportation, and manufacturing industries often value "hands-on" work learned through short-term training or on-the-job training and experience. While jobs in these industries have paid well in the past, the jobs which are now emerging in these industries either require more formal education or pay far less than they once did.

Individuals with a bachelor's or master's degree may not understand the desire to leave the relative comfort of a classroom to labor as a carpenter in the heat of the sun or operate a mining machine in the bottom of a dark, dusty mine. However, many workers find comfort of their own in physical labor, and the satisfaction of seeing their accomplishments stand before them on a job site at the end of a workday. Residents of rural areas often have acquired these values over generations through the work available to them where they reside. The challenge for the rehabilitation professional working with such individuals is to identify the skills and abilities necessary to perform physically demanding labor and help an individual apply those skills to training for more technical, less physical work.

In both urban and rural settings, there are individuals who do not enjoy school or formal training of any kind and prefer to learn through observation and demonstration. Often these individuals will perform better on measures of spatial perception, mechanical reasoning, and problem-solving than on measures of verbal aptitude and achievement. Because reading comprehension and verbal reasoning are important determinants of success in many formal education environments, individuals whose strengths lie in other areas often become frustrated and discouraged by schoolwork and formal education.

Individuals who experience difficulty with reading, writing, and arithmetic often dislike school and formal education generally. Older workers with these problems may view themselves as incapable of returning to school or training for alternate work. Older workers who experienced past success with skilled trades or manual labor positions may be frustrated by work requiring extensive reading or verbal abilities especially when that work is not accompanied by a similar level of earnings. For individuals faced with the challenge of overcoming lifelong learning deficits only to earn less money, the prospect of returning to the classroom may seem overwhelming and ultimately doomed to failure.

In rural areas which may be geographically or socially isolated from institutions of higher learning and where few individuals have more than a high school education, individuals may place higher cultural value on skilled trades or manual labor professions and less value on business, health care, clerical, and skilled technical professions which require a higher level of formal education. With incomes in rural areas lagging behind those in urban areas, the problem of funding higher education can be a significant barrier for rural residents (Marré, 2016). For individuals of modest means who know few friends or family members with college-level training, attending college or obtaining formal technical training may seem more like a dream than a practical reality.

Recommendations

Education, economic development, and creative uses of technology are factors that need to be considered as the economy transforms from the industrial, mechanical age to a digital and information age. As old jobs end or are phased out, new jobs are created. Building on the past without clinging to the past will assist all persons involved in rural rehabilitation, education, and training to find pathways to the future of rural America. One person or one discipline will not solve the problems of rural rehabilitation and economic development. The future resides in developing technological applications to secure a prosperous, productive, and enriching education and economic and social future for rural America.

Summary

Forensic vocational rehabilitation professionals perform a variety of services for rural individuals involved with civil litigation and entitlement programs. Areas of practice include worker's compensation, Social Security Disability, personal injury, wrongful death, domestic relations, and employment discrimination. Issues which are often addressed often include job functions, accommodations, work classification, disability legislation, and the availability of work.

Rural individuals may be unfamiliar with or intimidated by the vocational rehabilitation process. Rural individuals involved in forensic vocational rehabilitation often have performed more physically demanding labor than urban workers and may have had skilled or semiskilled work learned through more informal means such as on-the-job training and experience. Workers engaged in physically demanding or dangerous work may have shorter work lives than workers engaged in less physically demanding or dangerous work, even in the absence of injury or disability.

A worker employed in an industry or region in economic decline may be less likely to work in the future if they are unable to transition to work outside that industry or region. Changes in the economy and labor market have led to fewer jobs in rural areas as well as fewer well-paying jobs that do not require extensive training or skills. The low-skilled, low-wage jobs that are currently being created are often in the service industry which require different skills and temperaments than jobs in production, mining, and construction work.

Currently more jobs are being created in urban areas and for rural residents commuting or moving to an urban area may be difficult or impossible. Rehabilitation professionals may find that an individual is capable of working; however, the jobs for which that individual qualifies may be low paid or far away from rural residents. Availability of transportation and the ability to drive may be critical factors in an individual's return to work but not issues considered in some forensic rehabilitation claims.

Work preferences and self-concept may be limiting factors for some individuals especially males engaged in physically demanding, production, mining, and construction work. As service sector employment and skilled employment requiring higher education increase, individuals unwilling or unable to work extensively with others or complete formal training programs will have fewer employment opportunities. Access to education and training can significantly affect rural residents' ability to obtain and maintain employment. In some instances, individuals involved with substance abuse or the drug culture may be precluded from employment and be ineligible for entitlement programs which could help them obtain employment. In order to best serve individuals involved with forensic rehabilitation services, rehabilitation professionals should be aware of local opportunities and resources as well as barriers to employment, which exist in rural areas.

Rehabilitation professionals involved with forensic vocational rehabilitation must address a variety of issues and competing interests when making rehabilitation recommendations. Rural residents involved with forensic rehabilitation services are facing a changing labor market which is reducing the opportunities for employment in rural areas. Declining numbers of jobs in production, mining, and construction sectors present a barrier to return to work for individuals previously engaged in that employment. Declining wages for low-skilled work reduce the incentive for individuals to return to entry-level or unskilled work activities. As the skills needed for well-paying jobs increase, access to education becomes more important. Individuals with physical and mental disabilities living in rural areas have seen access to online education improve even as the prospects for work in rural areas decline. Rural residents may find that while they are capable of performing work which exists in the economy, that work may not be available to them where they live. Some rural residents are faced with difficult choices about whether to remain in the area with few employment opportunities or leave for areas where the work for which they qualify exists.

Resources

American Board of Vocational Experts (ABVE): http://www.abve.net

International Association of Rehabilitation Professionals (IARP): http://www.rehabpro.org. *Journal of Forensic Vocational Analysis*

National Association of Forensic Counselors: http://www.forensiccounselor.org

Robinson, R. H. (Ed.). (2014). *Foundations of forensic vocational rehabilitation*. New York, NY: Springer

Glossary of Terms

Administrative Law The branch of law governing the creation and operation of administrative agencies. Of special importance are the powers granted to administrative agencies, the substantive rules that such agencies make, and the legal relationships between such agencies, other government bodies, and the public at large. In forensic vocational rehabilitation, Social Security and worker's compensation claims are adjudicated through administrative law.

Civil Litigation A legal dispute between two or more parties that seek money damages or specific performance rather than criminal sanctions. In forensic vocational rehabilitation, personal injury, wrongful death, and employment discrimination claims are adjudicated through administrative law.

Eligibility Standard Criteria by which an individual is assessed for entitlement for benefits or inclusion in a specific group or class.

Entitlement A right to benefits specified especially by law or contract; also a government program providing benefits to members of a specified group.

Forensic Relating to, used in, or suitable to a court of law.

Essential Job Functions Used in conjunction with the Americans with Disabilities Act. The basic job duties that an employee must be able to perform, with or without reasonable accommodation. Essential job functions are typically identified in a formal job description. Factors to consider in determining if a function is essential include:

- Whether the reason the position exists is to perform that function
- The number of other employees available to perform the function or among whom the performance of the function can be distributed
- The degree of expertise or skill required to perform the function
- The actual work experience of present or past employees in the job
- The time spent performing a function
- The consequences of not requiring that an employee perform a function
- The terms of a collective bargaining agreement

Labor Market Survey	A report detailing the availability of jobs in a particular region or labor market typically related to a specific person. Labor market surveys typically include information about the numbers of jobs and employment rate in a specific region. Labor market surveys may include information about the exertion, skill level, duties, and essential functions of specific jobs they found through advertisements or job search websites.
Marginal Job Functions	A marginal job function is a job duty which is relatively incidental to the reasons for the job existence. A marginal job function could be removed from a job position without changing the fundamental nature of the job. A marginal job function is a duty that could be easily reassigned to another worker without disruption to the job or work environment.
Maximum Medical Improvement	MMI is defined as the point at which the injured worker's medical condition has stabilized and further functional improvement is unlikely, despite continued medical treatment or physical rehabilitation. A treatment plateau in the patient's recovery is reached and that is as good as the patient is going to get.

Learning Exercises

Self-Check Questions

1. What are the challenges facing rural forensic vocational rehabilitation practice?
2. What is the definition of forensic?
3. What is the difference between impairment of disability model and occupational disability model?

Experiential Exercise

1. Interview a forensic or vocational expert about the roles and function of his or her job.
2. Review the IARP Code of Ethics and compare/contrast it to another code of ethics (e.g., ACA, CRCC) to determine if there are competing points of interest.
3. Develop a paper of two to three pages on the importance of testing in forensic vocational disability assessment.

Multiple-Choice Questions

1. Which of the following cases is considered as the early case in which an expert witness was used as forensic testimony?
   (a) Republica vs. Democratica
   (b) Republica vs. Ross
   (c) Democratica vs. Smith
   (d) Smith vs. Ross
2. Which of the following best describes the options of workers when put in a position of a full-time job that will pay them a little more or even less than disability payments?
   (a) Work part time and earn less
   (b) Become disabled and retire
   (c) Work for less and become disabled
   (d) Become disabled and sue the employer
3. In rural areas, which of the following types of jobs pay more?
   (a) Physically demanding
   (b) Highway and roads
   (c) Textile
   (d) Recreation
4. Which of the following is a barrier of males residing in rural areas that need to transition from one occupation or industry to another?
   (a) Inflexible gender role expectations
   (b) Personal identity
   (c) Earnings
   (d) All of the above
   (e) None of the above
5. Which of the following best describes the initial expectation of a rural resident that is referred for forensic vocational services?
   (a) Believe he or she is being registered for disability payments

   - (b) Awareness of the purpose of the evaluation
   - (c) Expects to speak to a physician or psychologist about issues
   - (d) Aware of how long the evaluation process typically takes
6. Which of the following is the basis of services in forensic rehabilitation?
   - (a) Eligibility
   - (b) Entitlement
   - (c) Litigation
   - (d) Income
7. In which type of rehabilitation services are "order of selection" and severity of disability used to determine whether an individual will receive services?
   - (a) Proprietary
   - (b) Public
   - (c) Addictions
   - (d) Mental health
8. Which of the following is a vocational expert is asked to do in response to a claimant's testimony?
   - (a) Respond to questions posed about a hypothetical individual's ability to perform work based on specific limitations
   - (b) Respond to a claimant's residual functional capacity
   - (c) Respond to a claimant's request for an appeal
   - (d) Respond to questions posed by witnesses on behalf of the claimant
9. Which of the following describes the Social Security Disability standard for claimants in rural areas?
   - (a) The same standard is applied in rural areas as in urban and suburban areas
   - (b) Rural areas receive an exempt status
   - (c) Rural claimants need only to demonstrate that they can do work available in their local regional economy
   - (d) The standard for rural areas is determined by state law
10. Which of the following is a significant barrier of rural residents to relocate to urban areas?
    - (a) Type of disability
    - (b) Age of onset of disability
    - (c) Education attainment
    - (d) Social support

Key

1	B
2	C
3	A
4	D
5	C
6	B
7	B
8	A
9	A
10	D

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33

Climate and Weather in the United States and Its Impact on People with Disabilities in Rural Communities

Noel A. Ysasi, Irmo Marini, and Debra A. Harley

Overview

Individuals living in rural areas are often vulnerable due to physical isolation, economic diversity, increased poverty rates, and minimal healthcare options, especially for those with disabilities and the elderly (Hales et al., 2014). However, when human health is drastically influenced by weather and climate in addition to the aforementioned rural characteristics, PWDs face greater vulnerability. Specifically, extreme heat, severe winter storms, drought, wildfires (which increase air pollutants), floods, hurricanes, and tornadoes all contribute to the development or exacerbation of medical and mental health conditions. How well a community responds and has the resources available to handle inclement weather determines how PWDs will be impacted. For example, individuals with limited mobility (i.e., wheelchair users) are highly vulnerable when public transportation is only an option if one travels great distances. Rural localities, however, may have poor evacuation and emergency response procedures, lack adequate sidewalk and curb cuts, have dirt roads nonnegotiable for wheelchairs, and lack social or family support to help during extreme weather conditions (Balbus et al., 2016).

Although Chap. 25 focuses on natural disasters commonly encountered in rural areas, the purpose of this chapter is to specifically address weather and climate conditions (e.g., extreme heat and drought conditions) and its impact on PWDs residing in rural communities. The reader is encouraged to read this chapter and Chap. 25 as companion chapters. In this chapter, we focus particularly on six regions: Northwest, Southwest, Great Plains, Midwest, Southeast, and Northeast, each with varying weather and climate conditions affecting individuals differently based on type of disability and/or health condition. In addition, we provide an overview of four categories of extreme events which include the following: (a) heat and droughts, (b) wildfires, (c) winter storms and severe thunderstorms, and (d) flooding related to hurricanes and coastal storms. Understanding the changes in weather and climate, and the underlying exposure and sensitivity to these environmental conditions based on disability and illness, can

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N.A. Ysasi (✉)
College of Health and Human Services, Rehabilitation Services and Rehabilitation Counseling,
Northern Illinois University, DeKalb, IL, USA
e-mail: nysasi@niu.edu

I. Marini
University of Texas-Rio Grande Valley, School of Rehabilitation Services & Counseling,
Edinburg, TX, USA
e-mail: irmo.marini@utrgv.edu

D.A. Harley
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: dharl00@email.uky.edu

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improve the well-being outcomes when interventions and adaptation methods are provided in rural areas.

Learning Objectives
By the end of the chapter, the reader should be able to:

1. Identify common weather and climate conditions of each region within the United States.
2. Identify the weather and climate conditions and how they directly affect disability and health conditions.
3. Identify strategies for improving weather and climate health inequity in rural communities.

Introduction

Within the past 36 years, the United States has encountered precisely 196 weather and climate disaster events with losses exceeding 1 billion dollars for each (National Centers for Environmental Information [NCEI], 2016a, b). These events have consisted of 23 droughts, 24 floods, 7 freezes, 81 severe storms, 34 tropical hurricanes, 13 wildfires, and 14 winter storm events (NCEI, 2016a, b). In 2014, the Southwest experienced heat waves and droughts, the Northeast received over 20 inches of snow in certain parts of the region, the Southeast encountered severe weather outbreaks which brought tornadoes resulting in 5 fatalities and 50 injuries, and the Great Plains had one of the worst droughts in US history (NCEI, 2016a, b). For a person without a disability or health condition, finding shelter, lighting candles, gathering flashlights, or turning on a generator during a snowstorm may prove useful and be a practical solution. However, for those with disabilities who reside in rural communities, there may be the inability to gain access to a safe and secure location or higher ground (i.e., person uses a wheelchair). Power outages can affect health (i.e., bottles of insulin should not be kept in extreme heat or cold conditions, ventilators, power beds, etc.), and access to a quality healthcare provider after a storm has subsided may be unobtainable without available and accessible public transportation. These are just a few descriptors of the weather and climate conditions in the United States; however, when residing in rural communities in conjunction with having a disability, significant barriers and limitations are imposed upon this population. Before discussing disability and health in association with environmental conditions, we provide a brief overview of the six regions (aside from Alaska) along with population and disability rates for each. See Fig. 33.1 for the most common US climate trends.

Weather and Climate Conditions Along Six US Regions

Northeast

The Northeast region is home to more than 10 million rural residents with overall disability rates varying from 9.8% in Connecticut to 20.5% in West Virginia (as indicated in Table 33.1). Similar to other regions, the Northeast carries vast weather differences which range from extreme heat (which increases air pollutants), coastal flooding, river flooding, ice storms, droughts, and hurricanes. Climate change has also been a significant factor for increased heat conditions among states such as Maryland, Delaware, West Virginia, New York, and New Jersey, where projected temperatures above 90 °C are expected to increase (Melillo, Richmond, & Yohe, 2014). Within rural communities, there is a higher vulnerability to extreme heat as a result of housing construction, infrastructure, socioeconomic status (i.e., low-income families unable to afford air conditioning units), and type of disability (Melillo et al., 2014). For example, individuals with preexisting respiratory conditions are highly susceptible to infection and illnesses as a result of poor air quality related to extreme heat conditions and droughts (Melillo et al., 2014). The topography in this region varies significantly, where a vast number of rural areas have lower temperatures in the north and frequent

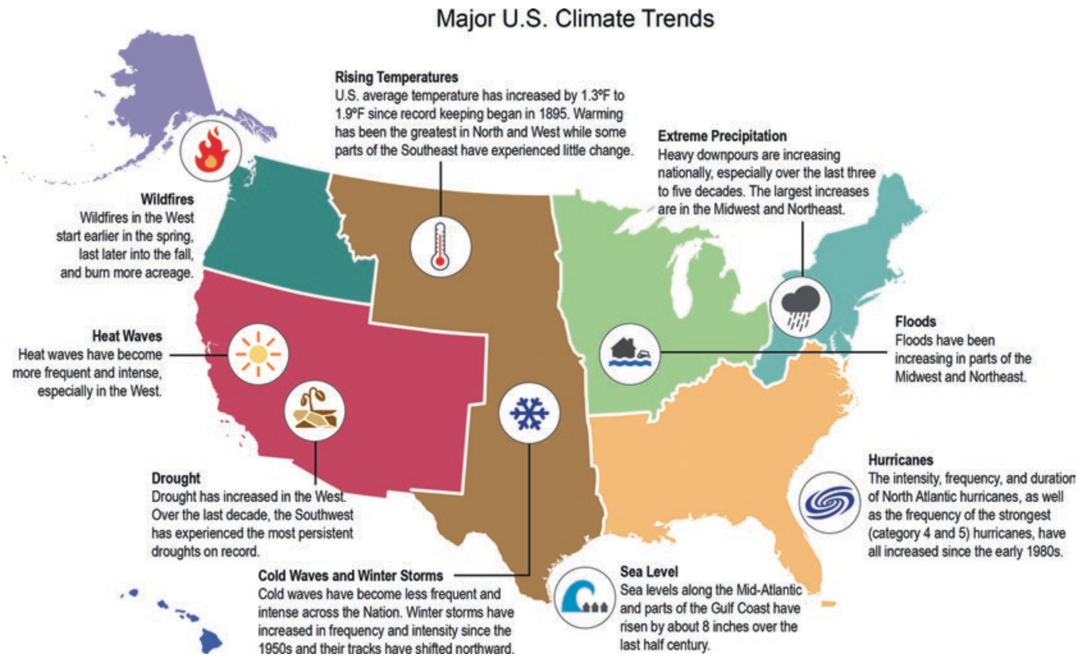

Fig. 33.1 Major US climate trends (*Note*: Adapted from "Climate change and human health," by Balbus et al. (2016))

Table 33.1 Northeast rural population and disability percentage

State	Total pop.	Urban/rural disabilities %	Rural pop.	% of rural pop.
Connecticut	3,574,097	11.2%/9.8%	429,155	12.01%
Delaware	897,934	11.8%/14.5%	149,985	16.7%
Maine	1,328,361	17.0%/15.9%	814,819	61.34%
Maryland	5,773,552	10.8%/11.4%	739,221	12.8%
Massachusetts	6,547,629	11.8%/10.2%	525,640	8.03%
New Hampshire	1,316,470	13.1%/12.7%	522,598	39.7%
New Jersey	8,791,894	10.4%/11.3%	467,768	5.32%
New York	19,378,102	11.0%/13.8%	2,349,997	12.13%
Pennsylvania	12,702,379	14.0%/13.5%	2,711,092	21.34%
Rhode Island	1,052,567	13.8%/10.1%	97,.524	9.27%
Vermont	625,741	16.1%/14.0%	382,356	61.1%
West Virginia	1,852,994	18.3%/20.5%	950,184	51.28%

Note: Adapted from: Stoddard (2014), U.S. Census Bureau (2010, 2015)

snowstorms in the winter. Yet summers in the south tend to be hot and humid with mild winter temperatures (Melillo et al., 2014). Nevertheless, the varying weather conditions (extreme heat waves, snowstorms, hurricanes, etc.) affect individuals with a wide range of disabilities (i.e., multiple sclerosis, spinal cord injury, rheumatoid arthritis, etc.).

Southeast

In 2010, the rural population within the Southeast region was nearly 17 million (US Census Bureau, 2010) with disability rates ranging from 11.2% in Georgia and 14.5% in Mississippi (Stoddard, 2014). Similar to the Northeast region, weather conditions differ as a result of geographic distribution, with weather conditions varying from extreme heat, droughts, hurricanes, tornadoes, and winter storms (Carter et al., 2014). Additionally, many states within this region (i.e., Louisiana, Mississippi, Alabama, Georgia, Tennessee, North Carolina, and Kentucky) have encountered extreme weather and climate occurrences that have resulted in more than a billion dollar in damages for each event over the past 30 years (NCEI, 2016a, b). For example, on August 14, 2016, one storm accounted for 31.39 inches of rain in Louisiana and Mississippi, affecting a substantial number of PWDs from being able to evacuate or utilize medical equipment requiring a power source (Liberto, 2016). In 2015, 3 days accounted for 160 preliminary tornadoes with 83 confirmed across Mississippi, Alabama, Georgia, Tennessee, and North Carolina, resulting in 46 reported fatalities and damages exceeding 1 billion (NCEI, 2015). Hurricanes are also highly prevalent in this region as Hurricane Isaac in 2012 flooded Louisiana, Missouri, Alabama, and Florida, ultimately killing nine people with damages estimated at 2.8 billion dollars (NCEI, 2015). Although the Southeast experiences droughts which substantially affect rural populations, states along coastlines (i.e., Louisiana, Florida, and South Carolina) are more vulnerable to flooding as a result of the aforementioned severe storms, tornadoes, and hurricanes. In comparison to other regions, PWDs are highly vulnerable to the extreme weather conditions in the Southeast due to vast number of populated areas and high disability rates. Details of the Southeast rural population and disability percentage can be found in Table 33.2.

Midwest

Representing 20% of the national total (61 million) and 13 million (21%) residing in rural communities (Pryor, Barthelmie, & Schoof, 2013; Stoddard, 2014), the weather conditions in the Midwest pose significant threats to public health. Specifically, this region consists of extreme heat waves and freezing temperatures, tornadoes, droughts, and increased humidity, and as a result of human-induced carbon emissions, air and water quality is relatively poor which has profound effects among PWDs. The emissions of greenhouse gases, for instance, are 20% higher than the national average and have been a significant contributing factor for increased temperatures exceeding 100 °C and increased pollen seasons (Pryor & Barthelmie, 2013).

Apart from the extreme heat and degraded air quality, flooding, tornadoes (e.g., approximately 1035 between 1991 and 2010), and winter temperatures falling below zero are quite common in this region (NCEI, 2016a, b). In 2008, flooding alone caused 24 deaths in the Midwest and accounted for 15 billion dollars in lost revenues from agriculture yields, damaged levees, and closure of transportation routes which affected distribution of goods (Pryor & Barthelmie, 2013). Moreover, in 2013 and 2014 alone, Michigan, Missouri, Iowa, Indiana, and Illinois encountered severe flooding which damaged thousands of cars, businesses, and homes and affected rural communities which rely heavily on agriculture (NCEI, 2016a, b). For details outlining the Midwest population and disability rates, please refer to Table 33.3.

Great Plains

The region is generally flatland; however, along the Continental Divide, elevation levels at the base of mountains generally go beyond 5000 feet above sea level (Shafer, et al., 2014). As a result of varying topography, the weather conditions can drastically differ. For instance, North Dakota, Kansas, and Texas can reach extreme heat conditions at 121 °F, while colder temperatures can be found in Montana hitting −70 °C (Shafer, et al., 2014). Aside from extreme heat and cold conditions, persons residing in this region are frequently challenged with winter storms, severe thunderstorms, drought, and rainfall which frequently result in floods (Shafer, et al., 2014). Disability rates also vary significantly in this region (i.e., 13.8–17.9%), with over 7.5 million people living in rural communities. The overall

Table 33.2 Southeast rural population and disability percentage

State	Total pop.	Urban/rural disability %	Rural pop.	% of Rural pop.
Alabama	4,779,736	15.5%/18.4%	1,957,932	40.96%
Arkansas	2,915,918	15.6%/19.2%	1,278,329	43.84%
Florida	18,801,310	13.1%/16.5%	1,661,466	8.84%
Georgia	9,687,653	11.0%/16.0%	2,415,502	24.93%
Kentucky	4,339,367	15.0%/19.9%	1,806,024	41.62%
Louisiana	4,533,372	14.5%/15.9%	1,215,567	26.81%
Mississippi	2,967,297	14.9%/17.5%	1,503,073	50.65%
North Carolina	9,535,483	12.5%/16.8%	3,233,727	33.91%
South Carolina	4,625,364	13.6%/17.5%	1,557,555	33.67%
Tennessee	6,346,105	14.1%/18.3%	2,132,860	33.61%
Virginia	8,001,024	10.4%/14.8%	1,963,930	24.55%

Note: Adapted from: Stoddard (2014), U.S. Census Bureau (2010, 2015)

Table 33.3 Midwest rural population and disability percentage

State	Total pop.	Urban/rural disability %	Rural pop.	% of rural pop.
Illinois	12,830,632	10.4%/12.8%	1,477,079	11.51
Indiana	6,483,802	13.8%/13.6%	1,786,702	27.56
Iowa	1,567,582	11.9%/12.0%	461,212	29.42
Michigan	9,883,640	14.4%/14.4%	2,513,683	25.43
Minnesota	5,303,925	10.8%/11.4%	1,417,614	26.73
Missouri	5,988,927	13.6%/16.8%	1,770,556	29.56
Ohio	11,536,504	13.9%/13.9%	2,546,810	22.08
Wisconsin	5,686,986	12.2%/11.4%	1,697,348	29.85

Note: Adapted from: Stoddard (2014), U.S. Census Bureau (2010, 2015)

impact such weather conditions have for PWDs can be life-threatening and will be discussed later in this chapter. For details outlining the demographic characteristics of each state, please refer to Table 33.4.

Southwest

Home to more than 7 million rural residents, the Southwest is considered the hottest and driest region in the United States and vulnerable to droughts, severe thunderstorms, flooding, and air pollution from wildfires (Garfin et al., 2014; U.S. Climate Data, 2016). Due to the extreme heat conditions, forest fires have increased by 650% in the Southwest and have contributed to health and safety concerns among residents (i.e., inhalation of smoke), loss of homes, and landslides as a result of erosion (Frisvold, Ma, & Ponnaluru, 2011; Morton, Roessing, Camp, & Tyrrell, 2003; Richardson, Champ, & Loomis, 2012; Western Forestry Leadership Coalition, 2010). Though the Southwest is generally known for their dry heat and droughts, some states such as Colorado are generally protected from these effects due to increased precipitation (Redmond, 2003). Other parts of the region, however, can encounter extreme flooding and erosion along the coast (i.e., California) as a result of rising sea levels and high tides (Garfin et al., 2014). With climate change in the hottest temperatures on record over the past decade, California is experiencing extreme drought, and what once was seasonal forest fire is now occurring almost all year round (Table 33.5).

Northwest

With rocky shorelines, volcanic mountains, and deserts, the topography in the Northwest varies substantially which contributes to the weather

Table 33.4 Great Plains rural population and disability percentage

State	Total pop.	Urban/rural disability %	Rural pop.	% of rural pop.
Kansas	2,853,118	12.5%/13.8%	736,157	25.8%
Montana	989,415	13.4%/14.2%	436,401	44.11%
Nebraska	1,826,341	10.7%/12.5%	490,655	26.87%
North Dakota	672,591	11.0%/10.2%	269,719	40.1%
Oklahoma	3,751,351	14.4%/17.9%	1,266,322	33.76%
South Dakota	814,180	11.9%/12.1%	352,933	43.35%
Texas	25,145,561	11.0%/14.8%	3,847,522	15.3%
Wyoming	563,626	12.2%/12.8%	198,633	35.24%

Note: Adapted from: Stoddard (2014), U.S. Census Bureau (2010, 2015)

Table 33.5 Southwest rural population and disability percentage

State	Total pop.	Urban/rural disability %	Rural pop.	% of rural pop.
Arizona	6,392,017	12.4%/16.7%	651,358	10.19%
California	37,253,956	10.4%/14.3%	1,880,350	5.05%
Colorado	5,029,196	10.1%/11.6%	696,435	13.85%
Nevada	2,700,551	13.3%/15.9%	156,754	5.8%
New Mexico	2,059,179	14.8%/15.4%	464,818	22.57%
Utah	2,763,885	9.7%/11.3%	260,290	9.42%

Note: Adapted from: Stoddard (2014), U.S. Census Bureau (2010, 2015)

conditions that can experience polar extremes from wildfires, snowstorms, and increased rainfall leading to flooding in lower valleys from the melting snow in the springtime (Mantua, Tohver, & Hamlet, 2010). Although this region can and generally does produce heavy rainfall (generally 12 inches more than most regions), it still does not compare to the yearly average of 47 inches in New York and 56 inches in Miami (Mass, 2008). The average temperatures and weather conditions differ based on geography (Kunkel et al., 2013; McGoldrick, 2011). For instance, winters in Oregon can reach an average high/low temperature of 49/37, while Idaho reaches 38/25 °C with average snow ranging from 5 to 10 inches per year in lower valley areas (U.S. Climate Data, 2016). Although seemingly quite mild, this region does bring about harsh winters accounting for severe ice storms in the Fraser River and Northwest Washington, freezing rain in the middle of the Columbia Basin, and large windstorms with winds ranging from 90 to 100 miles per hour (Kunkel et al., 2013) (Table 33.6).

Weather and Climate Conditions and Their Impact Toward Disability and Health

As demonstrated, weather and climate conditions vary significantly among each region, though some overlap does exist. Depending on social, political, and economic factors, otherwise known as social determinants of health, people and communities can be more vulnerable to health risks (Braveman, Egerter, & Williams, 2011). Even more so, PWDs have extreme challenges during severe weather and climate events which directly cause and/or exacerbate medical and mental health conditions. Though a few examples of extreme event types and their impact toward disability have been provided, we will explore the significance of extreme heat, droughts and wildfires, flooding, and severe winter storms among PWDs in rural and small towns.

Prior to discussing these four natural disasters, however, the reader should be aware of how federal, and in all likelihood, local municipalities are prepared to deal with emergency response and

Table 33.6 Northwest rural population and disability percentage

State	Total pop.	Urban/rural disability %	Rural pop.	% of rural pop.
Idaho	1,567,582	13.1%/15.4%	461,212	29.42%
Oregon	3,831,074	14.5%/18.1%	726,692	18.97%
Washington	6,724,540	12.3%/15.6%	1,072,671	15.95%

Note: Adapted from: Stoddard (2014), U.S. Census Bureau (2010, 2015)

rescue in the United States. Specifically, the September 11, 2001, attack and its aftermath drew to the awareness of those with disabilities during emergency response and rescue (ERR) from upper floors in high-rise buildings necessitated improved evacuation procedures since elevators were powered off. Subsequent to that event was Hurricane Katrina, where federal and local emergency response for all New Orleans citizens and surrounding rural areas was slow and ill-prepared for flash floods, bacterial floodwaters, and power outages lasting weeks. Despite the abovementioned occurrences and the Emergency Management Reform Act of 2006 (designed to plan and implement emergency evacuation and shelters equipped for persons with disabilities), enactment continues to be stagnant.

Weibgen (2015) in the *Yale Law Review* cited the fallout after the 2011 and 2012 respective hurricanes Irene and Sandy in New York and New Jersey. Emergency response and rescue and emergency shelters were not set up for urban or rural residents with disabilities. In the *Brooklyn Center for Independent Living of the Disabled v. Bloomberg* class-action lawsuit that followed, the city of New York was cited for numerous violations. Mayor Bloomberg and the city of New York were found guilty of cutting all transportation, not having a coordinated plan to evacuate those with disabilities, waiting over 2 weeks to send first responders to high-rise buildings without power, and providing no education to 311 and 911 operators on how to evacuate persons in wheelchairs. In addition, the judge cited “benign neglect” of persons with disabilities where shelters and other evacuation centers were either inadequate or inaccessible (Weibgen). This is one of two such lawsuits in the United States, and it remains highly likely that ERR and education for first responders are still woefully inadequate. The implications for these inadequacies for rural persons with disabilities become even more troubling in the event of natural disasters. In rural areas with scarce services, persons with disabilities may have to rely upon the kindness of family and neighbors to evacuate them or keep them safe.

Extreme Heat

High ambient heat occurs among all six regions and affects a substantial range of illnesses and mental health. Persons with preexisting medical conditions such as cardiovascular disease, respiratory disease, diabetes, asthma, obesity, mobility impairments, and mental illnesses are at increased risk for exacerbating their health conditions when exposed to extreme heat (Gamble et al., 2016). Mental, behavioral, and cognitive disorders can also be triggered or exacerbated by heat waves, specifically, dementia, mood disorders, neurosis and stress, and substance abuse (Balbus & Melina, 2009; Hansen, Nitschke, Ryan, Pisaniello, & Tucker, 2008; Martin-Latry et al., 2007; Page, Hajat, Kovats, & Howard, 2012). While both medical and mental health can be directly affected by heat waves, side effects from prescription medication and heat exposure can occur. Research has identified the association between increased temperatures, respiratory and cardiovascular conditions requiring hospitalization, emergency room admittance, and death (Gamble et al., 2016). Medications used to treat mental health disorders (i.e., depression, anxiety, etc.) can also interfere with the body’s ability to regulate temperature and increase susceptibility to the effect of heat, and dehydration from heat exposure can influence how medications such as lithium (used for bipolar disorder) are absorbed by the body (Berko, Ingram, Saha, & Parker, 2014).

When we think of infrastructure damage, we rarely consider heat waves as the resulting cause; however, consider the 2003 Northeastern blackout indirectly caused by a heat wave, leaving many rural communities without power for weeks (Bell et al., 2016). For PWDs who require an uninterrupted source of electricity, this can pose a significant health concern and reduce quality of life, and for individuals with physical disabilities utilizing assistive technology, mobility can be impaired (i.e., motorized wheelchairs require recharging from an electrical power source). Such power outages and rotating blackouts can be life-threatening for those with respiratory diseases or paralysis requiring a ventilator. For many with these disabilities living in rural areas and low income, backup generator and charged backup batteries are critical necessities.

In addition, those with certain types of disabilities such as tetraplegia, cerebral palsy, and other medical conditions where body temperature regulation is impaired, heat exhaustion and heatstroke can quickly become life-threatening if the individual is not in an air-conditioned environment with temperature control. PWDs with these types of chronic illnesses and disabilities also have to consistently drink fluids to hydrate and flush their bladder and kidneys to avoid urinary infections since their condition (i.e., paralysis and neurogenic bladder) poses an inability for them to void on their own. As indicated within the overview of the six regions, overall disability rates tend to be proportionately higher than urban communities, and with high ambient heat, a significant portion of PWDs in rural communities are affected across the country.

Droughts and Wildfires The Southwest, Southeast, Great Plains, and Midwest all experience droughts, while western regions have higher proportions of wildfires from extreme heat. Both contribute to reduced water quality, degraded air quality, reduced water quantity (only from droughts), and decreased life satisfaction, and, to a lesser extent, impact mental health (Bell et al., 2016). Of primary concern is the degraded air quality associated with wildfire smoke and air particles linked to droughts, affecting individuals differently based on age, illness, and type of disability. There is an increase in hospital admissions and deaths associated with cardiovascular and respiratory illnesses (e.g., asthma and chronic obstructive pulmonary disease) that involve decreased lung function (e.g., spinal cord injury at the cervical and thoracic level; Baja et al., 2010). While wildfires and droughts can worsen preexisting health conditions, they also account for premature deaths and increased risk for cardiovascular disease (Garcia, Yap, Park, & Weller, 2016; Gold et al., 2000; Pope et al., 2004, 2015). To improve health conditions from these effects, persons with the aforementioned health conditions should limit outdoor activities and decrease home ventilation to lower the inhalation of outdoor smoke (Laumbach, Meng, & Kipen, 2015; Weinhold, 2011). As noted earlier however, decreased life satisfaction is commonly associated with droughts and wildfires, particularly from the limitations imposed (i.e., reduced outdoor activity). Furthermore, research has indicated a strong association between these two event types and a negative impact toward mental health including grief/bereavement, increased substance use, and suicidal ideation (North, Ringwalt, Downs, Derzon, & Galvin, 2011).

In the case of wildfires in dry rural areas such as California often involving high winds, persons with mobility impairments are particularly vulnerable and must evacuate before the situation becomes dire. Rural disaster response and preparation for those with disabilities in most urban and rural areas across the United States are still inadequate despite Pres. George W. Bush's Executive Order in 2004 and enacted as the Emergency Management Reform Act of 2006 (Weibgen, 2015). Post Hurricane Katrina and the almost complete breakdown in federal and local emergency response preparedness for all Americans disabled and otherwise, the Emergency Management Reform Act was signed into law to better prepare these entities to evacuate and rescue individuals from such disasters as well as provide accessible shelter. Unfortunately, enacting this law has been slow to occur concerning those with disabilities, and as such, persons with mobility disabilities in fast-moving wildfire situations need to be evacuated many hours or perhaps days in front of the wildfire's path.

Flooding The Midwest and Northeast have the largest increases in flooding, particularly over the past three to five decades as a result of coastal storms and hurricanes. With over 10 and 13.6 million rural residents with high disability rates in the Northeast and Midwest, respectively, PWDs are more vulnerable to life-threatening situations and greater health risks from flooding. Specifically, high disability rates in these regions along with damaging infrastructure as a result of flooding impact health in a variety of ways. Although not a comprehensive list, examples of associated health risks as a result of flooding include the following:

- Traumatic injury and death from drowning (associated with flash flooding)
- Mental health impact (longer term)
- Respiratory illnesses
- Preterm birth and low birth rate
- Carbon monoxide poisoning from related power outages
- Blunt trauma from falling debris or quick moving objects in floodwater
- Electrocution
- Puncture wounds
- Burns
- Sprains/strains
- Hypothermia
- Water contamination
- Post-event disease spread from infrastructure disruption (Bell et al., 2016)

The aforementioned injuries and infections have been observed more commonly in rural areas (Špitalar et al., 2014). Because rural areas are highly susceptible to flash flooding conditions developing rapidly, these communities have reduced time to notify residents to respond and prepare during emergency procedures such as warnings, road closures, and evacuations (Bell et al., 2016). Furthermore, approximately 40% of country roads are inadequate for travel, bridges longer than 20 feet structurally deficient, and transportation safety continuing to be a concern (U.S. Department of Transportation, 2012); many rural residents are unable to evacuate during extreme flood events. Moreover, the ability to respond to a flooding emergency poses challenges for the aging population living alone and PWDs with mobility impairments and disabilities which reduce reaction time and require assistance (i.e., dementia, traumatic brain injury, Down syndrome, etc.). Flooding and all the other inclement weather conditions again involve the potential for power outages, and the concerns for those with disabilities requiring power were noted earlier.

Winter Storms Despite global climate change, the severity and incidence rate of winter storms have increased since the 1950s with snowstorms generally produced in greater frequency in the Northeast and Midwest regions of the United States (Bell et al., 2016; Francis & Vavrus, 2012). From loss of power to inadequate driving conditions, winter storms present an array of challenges for all persons residing in a rural community throughout the United States but pose greater challenges for PWDs. If you have ever experienced living in a geographical region which produces heavy snowfall each year, then you understand the environmental conditions generally require suitable preparation. For instance, the Department of Homeland Security (2016) recommends placing fuel-burning equipment in a well-ventilated area and purchasing at least 2 weeks of nonperishable food items during the winter season.

Infrastructure and access can be one of the primary challenges posed on PWDs during extreme weather conditions. The following infrastructure conditions and access during freezing temperatures are common barriers many people encounter which ultimately increase vulnerability:

- Older buildings with steep ramps
- Freezing pipes (eliminating running water)
- Poor road conditions (i.e., unpaved roads)
- Blocked roads and/or road closure from heavy snowfall
- Power outages for several days (affecting food, medicine, and overall personal safety)

These are just a few examples of infrastructure barriers and how PWDs can be affected as a result. Specifically, restoring power in rural communities can take several days as demonstrated in 2011 when a pre-Halloween snowstorm left several thousand homes affected in the Northeast region for approximately 10 days (Horton et al., 2014). In an effort to keep warm, individuals can resort to extreme measures, particularly through the use of gasoline-powered generators, charcoal grills, and propane heaters. All of which contribute to carbon monoxide poisoning and frequently associated with illness and death during the winter season (Bell et al., 2016).

Addressing Climate-Related Health Inequities

Governments in rural areas are generally ill-prepared to respond swiftly and effectively to extreme weather and climate events, although individuals and voluntary associations often show significant resilience. Health risks increase and can be aggravated by an ill-funded and/or inadequately trained healthcare system generally characteristic of rural areas, including long traveling distances to healthcare providers and the reduced availability of medical specialists (Hales et al., 2014). There are a few recommendations, however, provided by Friel (2013) which emphasize the need for community health organizations to focus their attention toward improving weather and climate health inequity. These include the following:

Evidence-Informed Practice

This form of practice is implemented to design health-promoting programs by obtaining reliable data on the extent of the problem and up-to-date evidence on the cause of health inequities. For the rehabilitation counselor, it means identifying the potential benefits, harm, and cost of an intervention program. What works in an urban community may not be practical in rural areas. Furthermore, bringing together local experience (i.e., PWDs who have encountered barriers and healthcare inequality) in addition to experts in developing health-promoting programs is ideal for ensuring the success of this practice.

People-Centered Practice

This method involves both person-centered thinking and planning. Rehabilitation counselors and community leaders should focus on the individual, identifying strengths and abilities, aiding individuals in connecting with their community, while identifying and addressing what PWDs are communicating as current barriers frequently encountered. For instance, persons with respiratory complications in need of uninterrupted sources of electricity to rely on medical equipment (i.e., portable oxygen), and have discussed their concerns with community leaders, should feel confident a plan is in place for addressing power outages in a timely manner.

Prevention-focused practice To appropriately address climate and weather conditions and its impact toward health equity, public health practitioners should focus on removing barriers toward access and quality healthcare. Rather than solely focusing on behavioral change (i.e., expecting consumers to find and/or adapt to climate and weather conditions), one should center their approach by preventing or ameliorating the disadvantaged circumstances that come with living in rural communities. One example would be to incorporate or increase home healthcare services for PWDs who reside in rural areas.

Summary

The unique need of rural Americans who live with various disabilities is an area that has received limited research and attention by the government regarding ERR planning and accessible safe haven shelters. Rural Americans with and without disabilities demographically often live in small towns with scarce social services including healthcare and funding for town infrastructure. Many rural residents deal with personal isolation and limited or no local healthcare clinics with highly trained staff and rely on volunteerism or the kindness of neighbors for assistance.

In dealing with natural disasters such as those described in this chapter, persons with certain disabilities become highly vulnerable in what may become a life-threatening situation or minimally to continue to be able to maintain their health. Persons with mobility impairments may experience little or no accessible travel options for expedient evacuation, and extended power outages may threaten the lives of those who rely on ventilators to breathe or whose temperature cannot be exposed to too hot or too cold weather conditions.

Town officials can better plan for inclement weather and emergency response by meeting with their residents with disabilities and plot a rescue response plan by including rural residents with disabilities in the process. Travel alternatives, backup generators, prescription medications, medical supplies, and making shelters accessible all must be included in such planning. Finally, planning for accessing trained medical providers in cases of emergency for residents with disabilities may literally become a matter of life and death.

Learning Exercises

Research Scenario

In a study conducted by Manangan et al. (2008), southern rural Georgia (Douglas, Vidalia, and Waycross communities) experienced more historic heat waves, had less access to hospital infrastructure (i.e., decreased adaptive capacity), and was reported to have an increased aging population living alone in comparison to other counties, thus increasing the vulnerability of southern Georgia's rural population (Manangan et al., 2008). However, the research failed to address the disability rates which account for 20.3% males and 23.9% females in Douglas, 23.5% males and 20% females in Vidalia, and 34% males and 28.6% females in Waycross (City Data, 2013), further increasing vulnerability among its rural residents in southern Georgia.

Research Scenario Question 1: Apart from identifying the demographic characteristics of an "aging population," and disability rates, what additional information would be beneficial to assess what factors increase vulnerability in a rural community? Hint: What specific issues exacerbate chronic health conditions and increase the probability of secondary complications occurring among people with disabilities? What specific chronic health conditions and illnesses are affected by extreme heat temperatures?

Experiential Activities

Below are two case scenarios. Read each one and respond to the questions.

Case Scenario I

John Cable is a 24-year-old rehabilitation client who has a C5 tetraplegia and ambulates by power wheelchair in a rural North Carolina town of 500 residents. You are seeing John today at his home where he resides with his elderly mother (his caregiver) as part of your monthly trip from Raleigh to visit your rural consumers who are receiving vocational rehabilitation services. Wilmington is the closest major urban area that is approximately 125 miles away. John is currently awaiting an accessible van that he can drive from his wheelchair but currently with no accessible travel options and no local public paratransit service. John is enrolled in an online education program and funded by vocational rehabilitation. On this day, a category three hurricane is 4 days away and has a 90% chance of hitting John's coastal town, and John is unaware because their television is broken.

1. Although not a part of your job duties, what steps can you take to make sure John and his mother will be okay?
2. How can you assist John and his mother in preparing for similar situations in the future?
3. What type of planning will you recommend? What strategies will you use?

Case Scenario II

Diagnosed at 6 months of age with cystic fibrosis, Colleen Silva is an 18-year-old high school graduate who is being visited by her transition counselor to determine her interests and goals to go to college. Currently, Colleen does regular home oxygen treatments and has a nebulizer and an inhaler. When the mucus becomes very thick, her lungs have to be suctioned with a suction machine. Colleen lives with her parents in a rural area about 85 miles away from the nearest urban center in Tulsa, Oklahoma. Her parents, who also have disabilities, had all the medical equipment funded from the Affordable Care Act; however, insurance rates are about to double and the family will no longer be able to remain insured. In assisting Colleen with her academic and vocational goals, your budget also allows for assisting your clients to maintain their health.

1. Knowing that Oklahoma is a highly volatile state concerning tornadoes and severe storms that often lead to power outages, how might you assist Colleen knowing that her rural town healthcare and social services are poorly funded and understaffed?
2. What are other resources you can identify for Colleen? Consider developing a resource manual.
3. What type of advocacy can you work with Colleen and her family in developing?

Key

Research Question 1 Answer Identifying the incidence rate of respiratory and cardiovascular illnesses and asthma, along with physical disabilities which directly impact respiratory health.

Options for Case Study I Answers (a) Contact the local authorities and emergency preparedness office in John's area and inform them of his current transportation situation and have him and his mother added to a list of residents that require "checking on" in the emergency and evacuation process. (b) Communicate with John's online instructor, inform him or her of the pending situation, and ask him or her to communicate with John as soon as possible. (c) If John has provided you with his emergency contact numbers, communicate with them as soon as possible. In each of these situations, it is not necessary to identify John as a VR client, only that you are aware of his situation.

Options for Case Study II Answer (a) Help to develop an emergency preparation and response plan, for example, having a backup power source such as a generator. It may be necessary to work with the consumer to identify funding sources to pay for it. (b) Recommend that she purchase her medication in a 3-month supply, rather than monthly. (c) Identify other funding sources to assist in paying for medical aids, and (d) work with community agencies and first responders to implement a registration system for people with disabilities, older persons, and those in need of assistance that would have a "check on" notification process in time of adverse weather or disaster.

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Part V

Education, Training, Networking, and Research on Vocational Rehabilitation in Rural, Frontier, and Territory Communities

34

Developing the Personnel to Meet the Needs of Persons with Disabilities in Rural Settings Through Online Learning

Jackie Rogers

Overview

The functions and knowledge requirements of rehabilitation counselors have changed over the years and have been surveyed on multiple occasions. A recent 2013 study (Leahy, Chan, Sung, & Kim, 2013) examined the important knowledge requirements and functions of Certified Rehabilitation Counselors (CRC). The knowledge domains identified as critical to rehabilitation counseling practice were (1) job placement, consultation, and assessment; (2) case management and community resources; (3) individual, group, and family counseling and evidence-based practice; and (4) medical, functional, and psychological aspects of disability. The three major job functions identified were (1) job placement, vocational assessment, and career counseling; (2) counseling, psychosocial interventions, and case management; and (3) demand-side employment, workers' compensation, and forensic services.

Although knowledge requirements are consistent across geographical locations, the reality of practicing in a rural environment may impact the manner in which counselors carry out the functions of a rehabilitation counselor. For example, lack of appropriate community resources and available professionals to serve the needs of individuals with disabilities within rural settings can result in delay or less than adequate delivery of services. Referral to medical, psychological, and similar service professionals may not be possible or may result in the need for the consumer to travel significant distances outside of the rural area to obtain such services. Lack of local educational institutions to provide training for consumers may impact the way in which a case is managed or a rehabilitation plan is implemented. These challenges require innovative thinking and training to surmount. Counselor education and training in the knowledge domains must include focus on serving individuals with disabilities across geographical locations including rural locations. However, rehabilitation counselors must still meet the requirements of a qualified rehabilitation counselor. In order to meet the educational and training needs of rural rehabilitation counselors, new methods of training delivery should be implemented. Online learning is one approach to ensure the attainment and proficiency in the important knowledge domains of rehabilitation counselors in rural settings.

The purpose of this chapter is to outline the challenges of serving a rural population and obtaining the training needed to provide services. The specific needs of adult learners in rural areas will be addressed. One approach to the preparation of students to practice in rural settings is the provision of online higher education.

J. Rogers (✉)
University of Kentucky, EDSRC Department,
Lexington, KY, USA
e-mail: jackie.rogers@uky.edu

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Learning Objective

By the end of this chapter, the reader should be able to:

1. Identify the professional challenges of working in rural areas.
2. Identify the reasons for personnel shortage of qualified rehabilitation counselors in state vocational rehabilitation (VR) agencies.
3. Identify characteristics of rural adult learners.
4. Identify ways in which distance education can be used to resolve the shortage of qualified rural rehabilitation counselors.

Introduction

The mission of the state-federal vocational rehabilitation program is to promote independence and the full integration of individuals into mainstream society, ideally in a state of optimal economic self-sufficiency (Rubin, Chan, & Thomas, 2003). The 1992 amendments to the 1973 Rehabilitation Act took steps to ensure the quality of services provided to persons with disabilities by establishing qualifications for rehabilitation counselors. Under these amendments, states were required to identify and define criteria necessary to be considered a "qualified rehabilitation counselor."

An existing standard of professional status in the field was identified as the Certified Rehabilitation Counselor (CRC) national certification. Since 1993, individuals taking the CRC exam must have a graduate degree in rehabilitation counseling or a related field and pass the certifying exam (Saunders, Barros-Bailey, Chapman, & Nunez, 2009). Many states adopted the CRC as the standard for being a qualified rehabilitation counselor. Alternative standards accepted included CRC eligibility, a master's in rehabilitation counseling, a master's in counseling or a related field, state licensure as a licensed rehabilitation counselor or licensed professional counselor, etc. Based on a review of the state plans, the majority of states require at least a master's degree in rehabilitation counseling, counseling, or a related field to be considered a "qualified" rehabilitation counselor.

Table 34.1 identifies the state requirements based on the 2015 state plans submitted to the Rehabilitation Services Administration (RSA) (US Department of Education, 2015).

National shortage of rehabilitation counselors The 2015 state plans also detailed the number of personnel by category that provide vocational rehabilitation services to the public, the current number of vacancies, and the projected number of vacancies for qualified rehabilitation counselors between 2015 and 2020. The state plans show there were 8910 rehabilitation counselor positions with state VR agencies throughout the nation. Eight hundred seventytwo (9.8%) of those positions were vacant and available. The projected number of vacancies for the next 5 years was 2894. Assuming the number of projected vacancies was not due to an increase in the number of positions, this would represent a 32.5% turnover rate within the state agencies between 2015 and 2020. This is an alarming rate of decline in qualified state agency personnel available to provide rehabilitation services.

Further compounding the shortage of qualified personnel is the fact that the number of graduates from programs in rehabilitation counseling seeking employment with state rehabilitation agencies is declining due to the availability of alternative employment options (e.g., private practice, colleges and universities, mental health centers, insurance companies, community rehabilitation agencies, federal veterans administration vocational rehabilitation program, etc.) A 3-year summary from summer 2008 through spring 2011 by the Council on Rehabilitation Education (CORE) revealed that 62.4–64.1% of graduates sought employment outside of state rehabilitation agencies. The Bureau of Labor Statistics for 2014 (U.S. Department of Labor, 2014) revealed that only 14.6% of rehabilitation counselors nationwide were employed by state agencies. The decline in available qualified personnel combined with the demand for agency rehabilitation counselors in the next 5 years poses a threat of decreasing quality and quantity of services to consumers with disabilities.

Table 34.1 State standards for meeting qualified rehabilitation counselor status

2015 qualified rehabilitation counselor standard	Number of states accepting standard
Certified Rehabilitation Counselor (CRC)	15
CRC eligible	14
Master's in rehabilitation counseling	24
Master's + CRC	3
Master's + CRC eligible	6
Master's in counseling	1
Master's in counseling + additional courses	4
Master's in related	8
Master's in related + additional courses	7
State licensed rehabilitation counselor	3
State licensed rehabilitation counselor eligible	1
Bachelor in rehabilitation + experience	4
Current master's student	1
Other	2

Note: some states accept multiple standards

Shortage of rural rehabilitation counselors The demand for rehabilitation counselors, similar to other social service and counseling disciplines, is more acute in rural areas. Frequently identified causes (e.g., aging out of professionals, relocating, or securing alternate employment outside of the state agency due to higher salaries) may be responsible for the shortage of rural counselors. However, other factors may also be present. Faubion, Palmer, and Andrew (2001) examined the demographic characteristics of counselors in urban versus rural areas and large versus small offices. The dimensions of age, years of education, years of experience, years in office, gender, major, licensure/certification, having a disability, and race were studied. No significant differences were found in these demographic attributes between the groups. If demographic attributes are not contributing to the decision to work in a rural location, perhaps intrinsic and extrinsic factors can account for the choice. Studies (Faubion et al., 2001; Oetinger, Flanagan, & Weaver, 2014) have surveyed the perceptions of mental health counselors working in rural areas. Rural counselors reported factors that drew them to living and practicing in rural areas include slower pace of life, natural surroundings for outdoor leisure activities, less crime, strong community support, independence, a strong work ethic, a desire to work with diverse disabilities and underserved populations, and prior experience living or working in a rural area.

Challenges to rural counseling Factors that negatively impact the decision to practice in rural areas may be the unique challenges faced by rural counselors. Challenges faced by counselors working in rural areas include demographic characteristics of clients, small town attitudes, service delivery issues, and professional barriers. Rural counselors report their caseloads are overly composed of individuals who are living at poverty levels and clients who have lower levels of education. Small rural communities often have negative attitudes about disability, a stigma associated with seeking counseling services, and a reluctance to accept or suspicion of “outsiders.” The lack of diversity or the acceptance of diversity within rural communities can also be a barrier for counselors desiring a practice with diverse populations. Population diversity in rural areas is increasing, however. The US Department of Agriculture (2015) reported that 21% of rural residents in 2014 were racial and ethnic minorities (http://www.ers.usda.gov/data-products/chart-gallery/detail.aspx?chartId=59547). The percent of minorities in rural areas was previously reported to be 19% in 2009 (http://www.ers.usda.gov/media/176091/page7.pdf).

Heavy caseloads and the lack of local supporting and referral resources such as healthcare providers, mental health facilities, training facilities, employment opportunities, and social support services present problems with service delivery. Lack of public transportation or adequate means of transportation is another issue that is commonly identified as a barrier to providing services to individuals in rural areas (Arnold, Seekins, & Nelson, 1997; Faubion et al., 2001; Lustig, Strauser, & Weems, 2004).

Counselors report professional barriers that interfere with providing services. Professional barriers identified by many counselors include the major problem of establishing boundaries and precluding dual relationships within a small community. Ethically, counselors should not engage in dual relationships with clients. However, in a small rural community, a counselor could easily find that clients are also members of the counselor’s church, parent organization, or other social organizations. There is a general lack of anonymity. The counselor must walk an ethical tightrope of maintaining professional boundaries in these situations (see Chap. 6 for additional discussion on ethics). Another professional barrier is the lack of readily available professional colleagues, supervisors, and mentors with which to communicate. This leaves counselors feeling at risk and can result in feelings of professional isolation (Breen & Drew, 2012; Oetinger et al., 2014). Finally, rural counselors often find that professional development and continuing education opportunities are not available locally and require that the counselors travel to metropolitan areas to remain current in their profession.

Training counselors to practice in rural settings Due to the shortage of qualified rehabilitation counseling professionals in rural areas, it is sometimes necessary for state agencies to hire personnel with lesser qualifications with the goal of securing additional training for those counselors to enable them to meet the qualification standards. This goal is complicated by (1) the lack of convenient local training and educational programs, (2) the time constraints of completing educational courses while maintaining full-time employment, and (3) the financial demands on personnel of paying for additional education.

Currently, there are 97 accredited graduate programs in rehabilitation counseling throughout the nation. Most of these are located in metropolitan areas. Individuals currently employed in a rural setting may not be able to commute to campus for the 2–3 years of full-time attendance required to complete the degree. State agency staff seeking to obtain their graduate degree in order to meet qualification standards are required to obtain their degree within a certain time frame and find it difficult to attend full-time courses while maintaining full-time employment. Although some state agencies have funded the additional training needed by their staff to meet the requirement, these funds are limited and often not available. Therefore, the staff encounters a significant financial demand to pay for additional education.

Increase in Adult Learners

State agency personnel who pursue additional education in order to meet state qualification standards are adult learners and nontraditional students, and these students have unique learning styles and needs. In higher education, the number of adult learners is increasing and appears to be poised to overtake traditional students. Collectively, adult learners define themselves as nontraditional students (Croix, 2012). The National Center for Education Statistics defines a nontraditional student as a student with at least one of these seven characteristics: (a) does not enter college immediately after high school, (b) attends part time rather than full time, (c) works 35 h a week or more, (d) is financially independent as defined by financial aid criteria, (e) has dependents other than a spouse, (f) is a single parent, and (g) lacks a high school diploma (though may have a GED or other high school equivalency) (http://www.nces.ed.gov). Adult learners are diverse in regard to several factors. First, they are variable, with a wide variety of learning experiences. Second, adult learners differ in their motivation (external versus internal) to learn. Third, the physical aspects of aging can impact the learner (i.e., sensory, energy, health). Fourth, characteristics including cognitive, personality, and socioeconomic factors impact an adult's ability to learn (Merriam, Caffarella, & Baumgartner, 2007). Finally, as the paradigm shift in age continues to be significant, adult learners find themselves crossing boundaries to start new roles and to explore new environments (Lakin, 2009).

More than half of nontraditional students enroll in 2-year institutions, and they are more likely to consider themselves working adults first and students second (Kaziz et al., 2007; http://www.worldwidelearn.com). In addition, adult learners may have started on a more traditional educational path and stopped with intentions to return, but work, family, financial need, or lack of previous success did not permit them to do so. Other circumstances such as multiple careers, fewer stable social structures on which to rely, longer life spans, dealing with aging parents, transportation, childcare, domestic violence, and the need to earn an income can serve as challenges for adult learners (Cercone, 2008). In fact, efforts to manage the complexities of career, family, and other personal choices often add to a somewhat chaotic educational and learning process.

Characteristics of adult learners Adult learners are heterogeneous. They return to school for a variety of reasons, and they span the age spectrum. All students come to school with a variety and range of work and experiences and educational backgrounds, which impact how and why they participate in learning (Wynne, 2013). In addition, adult learners usually approach learning differently than younger learners in that they (a) are more self-guided in their learning; (b) bring more, and expect to bring more, to a learning situation because of their wider experience and can take more away; and (c) require learning to make sense and will not perform a learning activity just because the instructor said to do it (Rochester Institute of Technology, 2012). It is important to remember that when it comes to learning, adults are not oversized children. They have a certain level of maturity, which brings unique characteristics that affect how adults are motivated to learn. While each student has individual learning needs, adult learners share a cluster of characteristics, which are generalized across the population.

Research on instructional design and e-learning suggests that adult learners tend to have a list of generalized characteristics as described below (http://www.fbe.unsw.edu.au/learning/instructionaldesign/studentslearn.htm#adult; http://theelearningcoach.com/learning/characteristics-of-adult-learners; Wynne, 2013). First, they are autonomous. Adults prefer a sense of control and self-direction. They like options and choice in their learning environment. Adult learners prefer to work at their own pace. Second, adult learners are goal-oriented and prefer to partake in learning activities that help them reach their goals. Third, adult learners are practical. Adults prefer practical knowledge and experiences that will help make their work easier or provide important skills. They tend to be impatient of busy work that does not have immediate and direct application to their objectives. Fourth, they like to gain competence and mastery in workplace skills as it boosts confidence and improves self-esteem. Fifth, many adults prefer to learn by doing rather than listening to lectures. Sixth, adults possess a wealth of knowledge that they acquired throughout life, and they bring this depth and breadth of knowledge to the learning situation. They are more realistic and have insights about what is likely to work and what is not. Adult learners are more readily able to relate new facts to past experiences. In addition, they enjoy having their talents and information used in instructional situations and like the type of learning that gives them practical activities that build on their prior skills and knowledge. Seventh, adults want to know the purpose of training and the motivation underlying an organization's training initiative. The eighth characteristic is that adults may exhibit several emotional responses to changes in job responsibilities or policies that require them to reengage in the learning process, and these emotions can interfere with the learning process. Ninth, they are result-oriented and have specific expectations for what they will get out of learning activities. Tenth, most adults have numerous responsibilities and commitments to family, friends, community, and work. Eleventh, depending on their age and physical condition, adult learners may acquire psychomotor skills more slowly than younger students and have more difficulties reading small fonts and seeing small images on the computer screen. Twelfth, adults require the big picture view of what they are learning and need to know how the small parts fit into the larger landscape. Thirteenth, adult learners often take responsibility for their own success or failure at learning. Finally, many self-directed adult learners prefer a learning community with whom they can interact and discuss questions and issues.

Adult learners are sometimes fatigued when they attend classes. Thus, they prefer teaching devices, a variety of methods, audiovisual aids, a change of pace, and a sense of humor that add interest and a sense of liveliness. They want anything that makes the learning process easier. In addition, adult learners are mature people and prefer to be treated as such. They learn best in a democratic, participatory, and collaborative environment. Adult learners need active rather than passive learning experiences. Unlike youth learners, adult learners are intrinsically motivated. They are motivated by internal incentives and curiosity. In addition, adult learners are motivated by the usefulness of the material to be learned and learn better when material is related to their own needs and interests (http://www.fbe.unsw.edu.au/learning/instructionaldesign/studentslearn.htm#adult). Another characteristic that distinguishes adult learners from youth learners is that adult learners are problem-centered rather than subject-oriented. That is, adult learners seek educational solutions to where they are compared to where they want to be in life as opposed to seeking to successfully complete each course, regardless of how courses relate to their own goal (Rochester Institute of Technology, 2012).

One of the major challenges of institutions of higher education is to understand how adult learners identify themselves. Adult learners want mobility and connection from family, education, work, and community (Lakin, 2009). To further understand adult learners, Cercone (2008) developed 13 characteristics of adult learners to consider when designing online instruction. Cercone's characteristics are grouped into the biology of adults, learning styles, experiential learning, self-directed learning, and transformative learning.

Barriers for adult learners Adult learners face a plethora of barriers that can affect their willingness, ability, and desire to return to school. Some of these barriers include career, childcare, family and financial responsibilities, rigid schedules and limited time, tight budgets (i.e., debt) and lack of money, poor academic preparedness and self-confidence, and lack of information and services (U.S. Department of Education, 2005). According to Croix (2012), "the same characteristics that define a nontraditional student all make it more difficult for that student to get an education" (p. 6). The vast majority of adult learners have work, family, and other responsibilities and find it difficult to free up time and dollars to attend school intensively (Kaziz et al., 2007). Moreover, the gap between high school and college and between undergraduate and graduate school means that nontraditional students may find themselves unprepared for the rigors of college or graduate-level coursework.

For adult learners, barriers may be specific to the learner (e.g., learner style, educational goals) and to the program, including student, organizational, faculty, and course barriers. In addition, participation barriers (i.e., situational, social-psychological, structural), personal barriers (e.g., childcare/elder care issues, financial issues), and a host of other barriers (e.g., cultural, political, geographic) may interfere with adults' ability to pursue higher education. In distance learning (DL), program barriers present the greatest challenge (Davis, 2009). Benders (2011) suggests that barriers for adult learners may not be true limitations in the concept of creating an obstacle that cannot be conquered, rather as emotional state of being or perceived inability. Nevertheless, even when barriers exist in the mind, they are formidable to accomplishing the intended task or knowledge base. In contextualizing the perceived barriers of adult learners in an accelerated undergraduate degree program, Deggs (2011) found three types of barriers: (a) intrapersonal, (b) career- and job-related, and (c) academic-related barriers. The results of the study suggest that barriers are never extinct for adult learners and they must work to overcome or manage barriers, which emerge from their multiple life roles.

Specific areas in which practices and policies shape how postsecondary institutions impact adult learners' success are accessibility, affordability, and accountability. Accessibility is concerned with how program structure and delivery in traditional higher education disadvantage working adults. Barriers relating to accessibility include time, flexibility, and instructional methods. Affordability focuses on how current patterns of student financial aid and institutional funding are inherently biased against adult learners, particularly those who work and attend school part time. "An American college education is said to be the most expensive college education in the world" (De Vito, 2009, p. 6). With a struggling economy, cost is a substantial issue for adult learners as well as what types of financial assistance is available to combat the cost of college. Accountability relates to how current formulas for greater accountability in higher education threaten to create and intensify institutional incentives that favor enrollment of traditional students over adult learners. Traditional students are often seen as the bread and butter (i.e., tuition) of universities. Accountability measures are intended to provide ways to assess program quality and to assist institutions to improve by identifying strengths and weaknesses (Kaziz et al., 2007).

Services adult learners need to be successful Adult learners not only expect but also need certain services that can facilitate their success as students. They need flexible class schedules, financial aid packages, childcare services, transportation options, course credit for life experiences, distance-learning options, accelerated class options, academic and career services, and education awareness campaigns that promote available education services (Nebraska Institute for the Study of Adult literacy, 2012). Often, adult learners returning to the classroom after years away need to "polish off some academic rust" and need assistance in writing and developing strong study skills. Adult learners may also experience many logistical challenges such as advising, paying a bill, purchasing books, or completing a drop and add transaction (Hill, 2011). Many of these challenges are mediated through electronic access.

Utilization of Distance Learning to Increase Supply of Rural Rehabilitation Counselors

Nontraditional and rural adult students have had a substantial impact on the way that higher education operates. The most significant impact is the increase in online educational programs. Online education is considered an important innovation in higher education design and delivery that is changing higher education products and services for all institutions (Kaziz et al., 2007). According to Croix (2012), the face of higher education will be reshaped by several twenty-first-century trends including (a) movement from a well-rounded education to a career-oriented work training model, (b) increase in time to degree is increasing for conventional degree programs and decreasing for fully online programs, (c) fast-track courses and intensive programs mean a new form of study, (d) fully online degree programs are numerous, and (e) government funding that favors the out-the-door-and-into-the-workplace model of education as job training. "Many adult learners want to take advantage of online learning environments, primarily due to busy schedules and the online format's convenience" (Cercone, 2008, p. 138).

The advent and increased availability of broadband Internet has allowed increased opportunities for the delivery of higher education training to rural communities. Currently, there are 31 online rehabilitation counseling graduate programs in the United States (http://www.gradschools.com/search-programs/online-programs/rehabilitation-counseling). The Council on Rehabilitation Education (CORE), which accredits only programs in the United States, is the accreditation body for these programs. CORE is recognized by the Council for Higher Education Accreditation (CHEA) and is a member of the Association of Specialized and Professional Accreditors (ASPA) (http://www.core-rehab.org/). Of these online programs, some are 100% online, while others are a combination of online and campus formats (Dziekan & Main, 2012).

Distance-learning programs offer several advantages toward meeting requirements for qualified rural rehabilitation counselors by including (a) multiple learning tools (e.g., print, graphics, audio, video, interactive activities); (b) learner self-pacing; (c) speedy interchange among learners; (d) ready access to a wealth of information, including libraries, databases, and other resources; (e) convenient accessibility for students with various disabilities; (f) instructors who are continually available to learners; (g) time for thoughtful contributions; (h) time for the instructor to guide the interaction with questions that promote analysis and evaluation; and (i) mentoring through personal electronic messages (Harley, Jolivette, & McNall, 2004). A distance-learning program is not restricted to particular states and is available on a nationwide basis.

Case Study of a Distance-Learning Program

The online program in rehabilitation counseling at the University of Kentucky was developed and designed with the rural adult learner in mind. The program began in 2004 and was the first and only fully online graduate program at the university.

Previously the university had provided graduate training to rural learners who were employed as rehabilitation counselors through live compressed-video courses conducted during evening hours. It was necessary for the students who had worked a full day to then attend classes for several hours after work. Although students were able to matriculate through the program, the average time frame for completion of the degree was 3 years compared to 16 months for traditional classroom students. This structure did not meet the needs of nontraditional students, who had employment obligations, family responsibilities, and other time constraints. An online distance-learning environment offered a means to overcome these barriers. The goal of the new online program was to provide a coordinated, cohesive, and accessible learning experience for nontraditional rural adult students that would provide relevant knowledge in an expeditious manner. To accomplish this goal, a sequence of steps was taken.

Structure of program The first step was to decide upon a mode of course delivery. Distance learning is an "institution-based, formal education where the learning group is separated, and where interactive telecommunications systems are used to connect learners, resources, and instructor" (Schlosser & Simonson, 2006, p. 1). Modes of distance-learning delivery can be synchronous (live), asynchronous, or a combination of both. Prior efforts with distance learning in this program had been synchronous. This mode of delivery did not allow the flexibility needed by nontraditional students to overcome the barriers of time constraints and family and work obligations. A primarily asynchronous format for course delivery was chosen as this allows the students to essentially be freed from the time constraints of attending face-to-face instruction. Students, who may be employed full time, are still able to complete the program in a reasonable length of time.

Although most coursework was presented asynchronously, certain courses (e.g., practicum and internship) were delivered through synchronous instruction and delivery (live videoconferencing) to comply with accreditation guidelines and to promote effective student clinical fieldwork experiences. Practicum and internship courses are designed "for the student to learn the skills and standards to prepare for a job as a counselor with the modeling and advice of a supervisor experienced in the field" (Morissette, Bezyak, & Ososkie, 2012). Section D of the Council on Rehabilitation Education (CORE) Accreditation Standards (2014) states, "D.3.1 When using distance education modalities, supervision may be provided using a variety of methods such as video conferencing, teleconferencing, real time video contact, or others as appropriate" (http://www.core-rehab.org/Files/Doc/PDF/CORE%20Graduate%20Standards%20and%20Self%20Study%20Document%2010-2014.pdf). The rehabilitation counseling program is able to connect rural students in practicum and internship sites through the use of real-time contact, thus allowing students to learn from each other's practical experiences.

Accelerated course format The second step was to insure that students could complete the program in a reasonable time frame. The demands of time, family, and resources on the nontraditional rural adult learner necessitated completion of an education program in an expeditious manner. For this reason, an innovative accelerated format was devised. To assist with employment and family obligation constraints of adult learners, students took two courses at a time versus four courses. The courses, normally taught during a 16-week semester, were taught in 8-week blocks. This accelerated format did not alter the course material or assignments, but still allowed students to complete the entire master's program in a 16-month time frame. The quantity of courses and amount of work and assignments were unchanged. The quality of the instruction was of primary concern, and courses were developed to ensure that campus instruction and distance-learning instruction were equivalent, i.e., the same syllabi, course material, course texts, and course assignments were used. Course lectures were equivalent in content and often completed by the same instructor for both campus and online courses.

Harley et al. (2004) have reviewed the use of an accelerated format of instruction. They concluded that an accelerated format would produce more counselors in a shorter period of time and would, therefore, create an immediate response to the CSPD requirements that rehabilitation counseling staff be "qualified." According to Harley et al. (2004) "accelerated DL can be an effective alternative to traditional formats" for counselors "who require lifelong learning and access to educational programs" (p. 125). In fact, Deggs (2011) states that awareness of the needs of adult learners has prompted higher education to design and implement accelerated degree programs. Student perceptions are generally positive in accelerated distance-learning courses and indicative of student satisfaction.

Cohort-based instruction Rural students often feel a sense of isolation and disconnect from centers of higher education and urban peers. Maintaining cohesiveness among students was considered an integral part of delivering distance-learning courses. For this reason, the program utilized a cohort-based instructional model. Truluck (2007) states, "Building a community is a necessity for online learning to succeed" (p. 3). In a cohort-based model, the students begin and end the program at the same time, following the same sequence of coursework, "which allows for greater interaction among students" (US Department of Education [DOE], 2006). Success rates have been observed to be higher in a cohort-based model than in a self-paced model (US DOE, 2006).

Coordination of program After establishing the structure of the online program, the next step was to hire a coordinator who would serve as an advisor and mentor to the students. Students who attend campus courses have the advantage of easy access to instructors, faculty, and peers that allows for frequent interaction and quick responses to program study problems, questions, or concerns. Rural students, however, do not have an equally easy access to these sources for mentoring and advising. The establishment of a coordinator of the program who would serve directly as the advisor and mentor to the rural and distance-learning students was an effort to increase access to these services. The coordinator monitored students from admission to graduation. The coordinator developed advising methods and procedures that would provide the students with a sense of community and promote retention in the program. The coordinator also developed orientation materials that would provide the student with not only essential information concerning university services and procedures but also with skills to matriculate through an online learning management system. Specific methods of mentoring provided included (a) live group orientation at the beginning of the program, prior to the initiation of field work, and prior to graduation; (b) provision of a detailed orientation manual which outlined the technological requirements, course procedures and expectations, university guidelines and services, sequence of coursework to be followed, procedure for requesting accommodations for disabilities, textbooks needed, procedure for registering for courses, and contact information for potential problems if encountered; (c) frequent individual advising sessions; (d) and development and implementation of a Virtual Student Advising Center for distance-learning students. The interaction and instruction provided through the advising, orientation, instructor discussions, internship supervision, and colleague interaction assisted in providing the students with overcoming the challenges of a rural work environment.

Course development and delivery Finally, courses were developed and offered. A course sequence that matched the on-campus program was implemented and included courses that addressed CORE accreditation guidelines. A special course in rural rehabilitation was also provided to prepare students to work in a rural environment. The course was designed to teach students how to understand the demographics of rural America and the incidence of disabilities in rural areas; be familiar with approaches, techniques, and instruments used in providing rehabilitation services in rural America; understand the unique challenges for the rehabilitation service provider when providing services in rural areas; be aware of the many ethical issues related to the rehabilitation professional providing services in rural areas; and gain knowledge of the American Indian Vocational Rehabilitation program.

To assist with the design and implementation of online courses, the University provided a Teaching Academic Support Center (TASC) with instructional design personnel. TASC was essential for successful development of online courses and provided instructors with assistance from initial planning through preparation and delivery of courses. It "ensures that the online learning experience is both enjoyable and productive for instructors and students alike" (Weiss, Schreuer, Jermias-Cohen, & Josman, 2004).

A consistent template was used in all courses to assist students with navigating through the learning management system, (i.e., Blackboard). This template was used specifically for formatting menu items and navigation through the course in a manner that did not impact course content delivery. Modes of instruction and assignments varied to insure that the students were stimulated to learn.

One aspect, however, remained consistent throughout all courses. A discussion board forum was provided to facilitate class interaction. Discussion board participation was seen as an important tool to connect students and instructors and to promote active participation in the course. For discussion boards, the instructor posted discussion questions or perhaps case studies for consideration. In most instances, students were then required to post their thoughts as well as respond to the posts of others and received a grade on their participation based upon a rubric. In other instances, discussion board participation was voluntary and not graded.

Accessibility issues for rural students Initially the program attempted to deliver Internet-based courses over all Internet connections. However, in some rural areas, students were limited by lack of access to broadband Internet connections. It was determined that the use of slower "dial-up" Internet access delayed delivery of the material, and therefore students were advised against using this method. This problem existed only in the first couple of years of the distance-learning program. Subsequently the availability in broadband connections has increased substantially, and rural students are no longer reporting difficulties in connecting to courses. Other accessibility issues encountered revolved around making courses accessible to students with disabilities.

The student population in the University of Kentucky's graduate program in rehabilitation counseling consistently includes a number of students with various types of disabilities. A primary concern for the distance-learning program was ensuring that all courses were accessible to all students. While this accessibility is a requirement of law under the Americans with Disabilities Act, the logistical components to providing this service proved challenging. The major issues associated with providing accessible courses were (a) captioning of asynchronous audio material; (b) live captioning of synchronous classes; (c) alternatives to timed quizzes and exams; (d) textual descriptions of visual presentations, i.e., charts, pictures, etc., used in courses; and (e) presentation of material in formats that could be read by computer-assisted technology.

It was essential to adopt a proactive versus reactive approach to course accessibility. With campus courses, accommodations are routinely made for students in a class on an as-needed basis. Students often do not inform the instructor of their need for accommodations until the first week of class. Procedures and vendors (e.g., sign language interpreters, note takers, etc.) for providing accommodations for campus students are in place and do not require a lengthy time to be initiated. Students in rural areas, however, may experience a lack of available interpreters or note takers in their geographical area resulting in a delay in coordinator of these services. Students in online programs can be located throughout the nation, and the need for accommodations is not always known by the instructor prior to the beginning of a course. There was discussion and debate over the need to provide completely accessible web material if a student with a disability was not enrolled in a course. However, federal law requires that all web material be accessible from the beginning. Further, speaking strictly from a time management standpoint, all material must be accessible from the beginning of a course especially if the courses are accelerated. Time to complete the transcription and captioning of audio material can take several weeks. In a course that lasts 8 weeks, this would create a distinct disadvantage for students with disabilities. Initially, courses made use of transcripts for asynchronous audio material for students with hearing impairments. While this is a temporary solution to alternative delivery of audio material, it is not recommended nor does it follow the guidelines of the federal legislative requirements.

Securing captioning services also proved to be a challenge. Although accessibility is a federal requirement, funding for captioning is generally not addressed or budgeted by programs. Since all captioning companies are not equal, it is important to evaluate the services provided by each company prior to selecting a vendor. In addition to cost-effectiveness, expediency and accuracy are essential. For example, several courses in the rehabilitation counseling program utilize medical terms. If a captioning vendor does not have a medical transcriptionist on staff, this can result in numerous inaccuracies in transcripts. Even the best transcriptionist cannot always understand dialects or accents of instructors or speakers. Therefore, it is also necessary that the transcribed material be reviewed and edited prior to the completion of captioning.

Technology issues were also present. In fact, the most frequent problem reported was related to technology. To address this problem, a 24 h help desk was implemented to assist students in overcoming technical difficulties. Also, required software programs for successful completion of the online program were made available to the students without a fee.

Student outcomes Student outcomes were reviewed within the distance-learning program and in comparison to the traditional campus-based program. A review of student outcomes must first take into consideration the differences between students who attended campus courses versus those that attended online. A demographic comparison of distance-learning students versus campus program students revealed several differences. The typical distance-learning student was employed full time in a rehabilitation agency, had been out of college for several years, and was unable to attend campus programs due to their remote location. The majority of campus students had obtained their undergraduate degree within 3 months to 1 year prior to enrollment. They were not employed full time or, if employed, worked part time outside the rehabilitation field. A small number of campus students had taken some graduate-level courses while still enrolled as an undergraduate. The average age of distance-learning students was 38.4 years, and the average age of campus students was 28.9 years. Within the 12-year span of students enrolled in the campus-based program, there has been a slight increase in the number of students who may be classified as nontraditional, older, and veterans. The distance-learning program consistently had students who were in this category. The DL program also saw an increase in the number of veterans enrolled in the program.

A review of student outcomes included (a) graduation rate, (b) grade point average (GPA) upon graduation, and (c) competency evaluation of graduates based upon the pass rate on a nationally certified examination (Certified Rehabilitation Counselor exam). From January 2004 through December 2012, 406 students began the accelerated distance-learning program, and 364 of those graduated (89.6% program graduation rate). Distance-learning students who were enrolled full-time graduated in the same amount of time as campus counterparts. The length of time to completion was 16 months. There was no significant difference (3.78 on a 4.0 scale for distance-learning students and 3.83 for campus students) between the grade point average (GPA) upon graduation. The pass rate on the national certification examination for both campus and distance-learning students was consistent and exceeded the national average. There has also been an increase in the frequency at which campus and distance-learning students have expressed an interest in pursuing additional credentials to become licensed professional counselors. Overwhelmingly, upon graduation, distance-learning students remained employed with public rehabilitation agencies, and on-campus students obtained employment with state rehabilitation agencies, nonprofit rehabilitation programs, disability resource programs in postsecondary education, and in medical, corrections, and veterans administration positions. In some instances, both campus and distance-learning students matriculated to administrative positions.

Summary

Lack of rural educational institutions that provide graduate training in counseling fields contributes to difficulty finding available qualified personnel to meet the demand for rehabilitation counselors. Innovative approaches to recruitment and training of individuals willing to serve in rural areas must be undertaken by state agencies. Research has shown that individuals with prior experience living in rural areas are more inclined to practice in rural areas upon graduation. The individuals from rural backgrounds may be reluctant to relocate temporarily to metropolitan areas where educational facilities are generally located to receive the necessary graduate training in counseling. One potential method of training rural counselors is the use of distance-learning programs. By providing distance education training and continuing education for individuals residing in rural areas, this obstacle is resolved.

Funding for rehabilitation counseling distance education programs has been supported in recent years by the Rehabilitation Services Administration. The agency implemented training funds that paid the educational costs for individuals seeking employment as state VR counselors. Most of these grants, however, did not include a provision that the graduate work in rural areas. Therefore, there was little impact on the recruitment of qualified graduates to work in rural America. Another source of funding is student loans. Teacher and physician education student loans have provisions to encourage practice in rural settings. In particular, a portion of the student loan debt is forgiven for each year the professional practices in a rural area. A similar program designed for rehabilitation counselor and other mental health professionals could act as an incentive to becoming rural counselors. The provision of loan forgiveness has been shown to increase the chances of selecting a rural practice among physicians (Daniels, Vanleit, Skipper, Sanders, & Rhyne, 2007). Phillips, Quinn, and Heitkamp (2010) found similar results in the recruitment of social workers to rural areas.

Other methods of training rehabilitation counselors to work in rural areas may be easier to implement. One method is for educators to provide a particular course or courses addressing the unique aspects of counseling in the rural sector. This would be beneficial in preparing counselors to acclimate to the rural culture. Learning to identify the challenges to the provisions of services and how to potentially overcome those barriers is essential to preparing the counselor for rural practice. Boundary and ethical issues inherent in rural settings must be addressed in order for the counselor to function effectively.

The reluctance to practice in rural areas is often a result of persistent negative stereotypes and non-exposure to rural communities. One study (Phillips et al., 2010) revealed that social work students recommended that rural social workers speak to classes to help “dispel stereotypes and excite interest in rural practice” (p. 57). Another method of training could be the provision of graduate field experience, i.e., a practicum or internship, in a rural setting. This could serve to alleviate the reluctance to practice in the area. Students should be provided with the opportunity to experience those aspects of rural life that have been shown to draw professionals to rural practice, i.e., slower pace of life, less crime, natural surroundings for outdoor leisure activities, strong community support, independence, a strong work ethic, and an opportunity to work with diverse disabilities and underserved populations.

The provision of distance-learning graduate programs in rehabilitation counseling can assist state rehabilitation agencies in implementing a “grow-your-own” approach to developing counselors in rural areas. For example, in rural areas agencies should consider recruiting persons who live in the area as paraprofessionals, provide training to them, and recruit or support them in educational endeavors that eventually lead to obtaining the credentials to meet the standards of a qualified rehabilitation counselor. Such efforts can be planned in conjunction with RSA and other state human service agencies.

Provision of ongoing supervision and mentoring by senior staff on a regular, consistent basis should be provided to rural counselors. Breen and Drew (2012) suggest that such support is essential to alleviate isolation and maintain effective rural practice. Opportunities for continuing education should be provided to negate the effects of professional isolation. Distance-learning courses and webinars can assist with providing these opportunities.

The demand for rehabilitation counselors continues to exceed the supply of available qualified rehabilitation counselors. The need for qualified rehabilitation counselors in rural areas is seen as acute. Overcoming the reluctance of rehabilitation counselors to practice in rural areas is essential to securing appropriate professional services for individuals with disabilities who reside in these areas. Various techniques and programs can be considered to assist with meeting this demand. The provision of graduate training through distance learning is one step in addressing the challenges faced by rural counselors. In addition, increased exposure to rural areas and professionals from rural areas, provision of ongoing supervision and mentoring, and financial compensations or incentives can begin to address challenges faced by rural counselors. In order to achieve success in increasing the supply of qualified rural rehabilitation counselors, concerted efforts of both rehabilitation counseling educators and rehabilitation state agencies must be taken to insure that rural consumers with disabilities are provided with needed services by qualified rehabilitation counselors.

Resources

Evaluating the Impact of Rural Universities on Local Communities (February 12, 2015) is a complication of seven group projects written by MBA students enrolled in a management and organization course in the Eastern Oregon University's College of business MBA program. Available at https://www.eou.edu/rural/files/2015/02/Evaluating-the-Impact-of-RuralUniversities-on-Local-Communities.pdf

Open and Distance Education Policy Briefing (2013). International Council for Open and Distance Education. Available at http://www.icde.org/assets/AboutUs/Who_we_are/OpenandDistanceEducationPolicyBriefingMarch20133.pdf

Renes, S. L. (2015). *Increasing access to higher education through e-learning*. InTech Open Science/Open Minds. Available at http://cdn.intechopen.com/pdfs-wm/48959.pdf

Skillman, S. M., Keppel, G. A., Patterson, D. G., & Doescher, M. P. (2012, October). *Final Report #136: The Contributions of Community Colleges to the Education of Allied Health Professionals in Rural Areas of the United States*. Available at http://depts.washington.edu/uwrhrc/uploads/RHRC_FR136_Skillman.pdf

United States Distance Learning Association (USDLA): https://www.usdla.org

USDLA Quarterly Journals: https://www.usdla.org/resources/usdla-quaterly-journals/

Learning Exercises

Self-Check Questions

1. What are the reasons rehabilitation counseling graduates are not pursuing employment with state rehabilitation agencies?
2. What are the problems found in the case study with providing accessible distance education courses?
3. What are some methods that can be used by counseling educators to assist in recruiting rehabilitation counseling graduates to work in rural areas?
4. What are some ideas that state rehabilitation agencies could implement to recruit rehabilitation counseling graduates to work for their agency in rural areas?

Experiential Exercises

1. Identify a rural area in your state and determine the prevalence and types of disabilities that exist in the geographical location from government sources.
2. Identify a rural area in your state, and outline the rehabilitation service providers, community, and support services available for the area. Compare these findings with providers and services in a major urban area in your state.

Discussion Box

Discuss the use of distance learning to increase the supply of qualified rehabilitation counselors. What are potential advantages and disadvantages of using distance education to increase the supply of rural rehabilitation counselors? How could distance education methods be improved to increase delivery of continuing education to rural counselors?

3. Identify the educational graduate school programs in rehabilitation counseling, counseling, or a related field available in your state. Indicate which of these programs/universities are within commuting distance (75 miles) of rural state areas.
4. Design a study to investigate the effectiveness of rural internships in recruiting graduates to work in rural areas.

Multiple Choice Questions

1. Based on state plans submitted in 2015 by state VR agencies, what credential/education is required by the majority of states to be considered a "qualified rehabilitation counselor?"
   (a) CRC credential
   (b) LPC credential
   (c) Master's degree in rehabilitation counseling, counseling, or a related field
   (d) All of the above
2. Federal mandates to ensure the quality of services provided to individuals with disabilities by establishing qualifications for rehabilitation counselors was a result of which of the following Acts?
   (a) Rehabilitation Act of 1973
   (b) Rehabilitation Act Amendments of 1992
   (c) Americans with Disabilities Act
   (d) Civil Rights Act
3. Which of the following is a reason for shortages of qualified rehabilitation counselors in rural areas?
   (a) Aging out of professionals
   (b) Reluctance of graduates to pursue employment with state VR agencies
   (c) Reluctance of graduates to practice in rural areas
   (d) All of the above
4. Which of the following are challenges to providing rehabilitation services to rural communities?
   (a) Characteristics of clients and professional barriers
   (b) Small town attitudes, service delivery issues, and reduced salaries for counselors in rural areas
   (c) All of the above
   (d) None of the above
5. What demographic characteristics of counselors have been found to contribute to the decision to work in rural areas?
   (a) Age, years of education, and years of experience
   (b) Gender, having a disability, and race
   (c) College major and licensure
   (d) All of the above
   (e) None of the above
6. State agency personnel who pursue education in order to meet qualification requirements are generally which of the following?
   (a) Adult nontraditional students
   (b) Students who have completed an undergraduate degree in the last year
   (c) Personnel wishing to pursue administrative positions within the agency
   (d) All of the above

7. Which of the following is NOT a primary barrier that can affect the decision of adult learners to return to school?
    (a) Career, childcare, and family responsibilities
    (b) Lack of self-confidence and academic preparedness
    (c) Limited time and budget
    (d) Limited commitment to pursue higher education
8. Which of the following is true regarding distance education graduate programs in rehabilitation counseling?
    (a) They are not approved by the Council on Rehabilitation Education.
    (b) They are presented only in a live format during daytime hours.
    (c) They can be presented in a synchronous, asynchronous, or live format.
    (d) They restrict the student enrollment to in-state students.
9. Which of the following best describes accelerated mode of distance-learning instruction presented in the case study?
    (a) Condensing course length from 16 to 8 weeks
    (b) Allowing students to progress through courses in a self-paced format
    (c) Reducing the amount of material and courses necessary to secure the degree
    (d) Allowing students to waive certain educational electives to complete a degree in a shorter time frame.
10. What effect did the funding of training for rehabilitation counselors by the Rehabilitation Services Administration have on the recruitment of rural rehabilitation counselors?
    (a) Resulted in a major increase in rural counselors
    (b) Produced a moderate increase in rural counselors
    (c) Had little impact on the recruitment of rural counselors
    (d) Doubled the number of rural counselors

Key

1. c
2. b
3. d
4. c
5. e
6. a
7. d
8. c
9. a
10. c

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35

Human Resources Issues: Recruiting and Retaining Rehabilitation Counselors and Human Service Professionals in Rural, Frontier, and Territory Communities

Allison R. Fleming

Overview

The need for rehabilitation counselors and other allied health and human service providers in rural areas continues to exist as individuals face psychosocial, medical, economic, and other life challenges. For individuals with disabilities, rehabilitation counselors are able to provide direct services, as well as refer out and coordinate services. Currently, each state employs rehabilitation counselors in federal-state vocational rehabilitation agencies and blind services. In addition, rehabilitation counselors can be found in various work settings. The demand for credentialing qualified rehabilitation counselors is reflected in the number of Council on Rehabilitation Education (CORE) and Council for Accreditation of Counseling and Related Educational Programs (CACREP) accredited training programs in the country. Today, in an era of decreasing allocations for human services and increasing demand for services, rural areas are disproportionately affected not only in available resources for clients but in adequate numbers of personnel to deliver services.

The recruitment and retention of rehabilitation counselors in rural areas often requires the counselor to be a generalist with a working knowledge and skills in a variety of rehabilitation issues. Counselors must be adept in a variety of rehabilitation and job placement duties as opposed to their urban counterparts who are often more specialized. Counselors and human resource departments are aware of the barriers to recruitment and retention of personnel in rural areas. Recognizing the challenges, however, of rehabilitation counselors in rural areas, the strategies to recruit and retain counselors should temper them with a strong emphasis on the positive features of service delivery in rural areas**.**

Learning Objectives

After reading this chapter, the learner should be able to:

1. Explain the negative consequences associated with staff shortages and turnover in rural communities.
2. Understand strategies for recruiting rehabilitation professionals to work in rural communities.
3. Understand strategies to retain valued employees working in rural communities.

A.R. Fleming (✉)
Pennsylvania State University, Rehabilitation and Human Services, University Park, PA, USA
e-mail: apf508@psu.edu

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Introduction

In human resources, recruitment and retention of qualified staff is a constant pressure. Unlike in metropolitan areas where there is a concentrated population, more outlets for socialization, shopping, and entertainment, the process of recruitment and retention is different in rural, frontier, and territory communities where fewer people reside. Recruitment needs are great; several demographic shifts such as the aging population, increasing numbers of veterans returning from service with rehabilitation needs, and increased life expectancy for persons with many disabilities and chronic illnesses mean that more people need rehabilitation services than ever before. Since the "applicant pool" in rural areas is smaller, retention of counselors becomes critically important once a qualified person has been hired. For the community, service providers are more than just the availability of the service(s), they also provide infrastructure to the community and are a source of employment (O'Toole & Schoo, 2010). The job outlook for rehabilitation counselors in the USA is positive; figures from the Department of Labor indicate that growth is projected at faster than average for all occupations through 2024 (estimated 9% growth; US DOL, 2015). Rehabilitation counselors work in both public and private settings, including for and not for profit organizations. They may work with children and families, youth and teens, working-age adults, or older adults. Rehabilitation counselors may support vocational, educational, independent living, or physical or mental health-related goals. Yet, the ability to recruit and retain qualified rehabilitation counselors in rural, frontier, and territory areas remains a challenge (Table 35.1).

Table 35.1 Top industry settings for rehabilitation counselors

Setting	Percentage of industry	Hourly mean wage
Vocational rehabilitation services	9.87	$16.78
Residential facilities	1.82	$15.47
Individual and family services	1.07	$16.79
State government	0.74	$23.35
Local government	0.10	$21.05

Source: US Department of Labor (2015)

In the rehabilitation counseling discipline, recruitment and retention poses a significant challenge to rehabilitation agencies in rural and urban settings alike. Contributors include increasing retirement rates, reduced numbers of graduates from rehabilitation counseling programs, and ongoing staff turnover (Armstrong, Hawley, Blankenship, Lewis, & Hurley, 2008). Reports of job satisfaction among rehabilitation counselors have been mixed (Armstrong et al., 2008; Layne, Hohenshil & Singh, 2004), and identified reasons for turnover include lack of advancement opportunity, work overload, poor compensation, and high levels of stress and burnout (Armstrong et al., 2008; Barrett, Riggar, Flowers, Crimando, & Bailey, 1997; Layne et al., 2004). Burnout is a term frequently used in the human services and healthcare fields characterizing the emotional exhaustion that results from the high demands placed on professionals; burnout may include physical, emotional, and/or mental exhaustion (Layne et al., 2004). Although burnout may be substantial among rehabilitation counselors and other human service providers, research suggests coping resources are a protective factor against burnout (Layne et al., 2004).

The issues of recruitment and retention are intertwined. Turnover is costly and detrimental to both the agency itself and clients. Providers functioning with insufficient staff are less likely to achieve organizational goals, and the stress put on other staff when a caseload goes uncovered puts the agency at risk to lose additional employees. For clients, insufficient contact, gaps in support, and the strain associated with getting to know a new provider are all consequences of staff turnover. Counselor job satisfaction has been linked to consumer satisfaction (Capella & Andrew, 2004), meaning that unhappy staff have the potential to negatively influence clients. Recruiting for retention (Rural Health Information Hub, 2014) is a strategy recommended where agencies recruit staff that are a good fit for the agency and community and then continually work to retain them. The following is a discussion of the challenges inherent in the recruitment and retention of rural counselors and approaches that promote recruitment and retention.

Challenges in Recruitment and Retention of Rural Counselors

Much like other allied health and human services, the availability of rehabilitation services typically declines as the population density decreases. This issue is compounded with the higher rates of age-adjusted disability, chronic health conditions, and mortality than residents in rural areas (Jones, Parker, Ahearn, Mishra, & Variyam, 2009). Professionals in related fields have noted a trend toward practitioners recruited from cities coming to work for a few years in rural areas and then leaving, thus resulting in rural areas earning the reputation as "professional nurseries" (Schoo, Stagnitti, Mercer, & Dunbar, 2005) or places where new clinicians gain experience and learn skills but typically do not stay. Considering the learning curve associated with counseling and human service positions, retaining counselors past their training years is desirable, as this is when clinicians are more experienced and may be more effective. For this reason, authors suggest focusing on factors that attract and retain clinicians who want to live in rural areas rather than those who would prefer to live in urban or suburban locales. In fact, Mackie and Simpson (2007) found bachelor's-level social work students more likely to seek rural employment if raised in rural communities and expressed greater comfort with living in rural settings, express a desire to raise family in rural communities, feel there is greater sense of community in rural areas, and want to work to improve the quality of life among rural residents. In a study predicting who is more likely to become a social worker in rural areas, Mackie (2007) found students raised in rural areas, participated in rural-based practicum or internship, and received education and training in rural-specific content. It is important to recognize that just as urban and rural areas differ, all rural areas are not the same.

In addition to the expense of continually recruiting and training professionals who do not stay on the job long term (Chisholm, Russell, & Humphreys, 2011), it is disruptive and potentially damaging to clients to continually lose a provider and have to begin services with another person. Negative perceptions of the rural environment, distance from family and friends, lack of social activities and entertainment, and travel costs are all listed as top drawbacks of pursuing positions in rural areas (Schoo et al., 2005). Other considerations are pay, availability of supervision and professional development, and sufficient numbers of clients to build a full caseload/practice (O'Toole & Schoo, 2010). For professionals who wish to live in a given area, the motivation to stay with a particular service provider is strong – unlike urban centers, there are fewer employment opportunities. This often creates stability within providers and agencies, which is a great benefit to professional partnerships and clients alike.

Research Box 35.1 See Sidwell et al. (2006)

In order for agencies in rural areas to recruit and retain qualified candidates, it is important to understand what workers perceive as the most desirable and most challenging aspects of their work. This information is best gathered directly from professionals and may be accomplished through a qualitative approach. The article featured here is based on qualitative survey data gathered from social workers employed in rural counties in Pennsylvania ($N = 113$).

Objective or research question: This was an exploratory study aimed to find out why rural social workers choose to live in these areas and how they describe their jobs and their experiences. This information was gathered to apply to recruitment and retention to social workers and other human service professionals in rural communities.

Method: Researchers mailed surveys to social workers in 14 rural counties in

Pennsylvania. Close and open-ended questions were included to gather perspectives on the desirable and challenging aspects of serving rural communities. One-hundred and thirteen professionals responded to the survey, for a response rate of 65%.

Results: Respondents reported the reasons that they choose to live in rural areas included: relationships (e.g., family ties), the surroundings and lifestyle (e.g., I enjoy the community), and employment (e.g., own or family members job is in this community). In response to the question about the benefits of working in the rural setting, two themes emerged, one was about work and the other related to the community. Responses regarding the work indicated enjoyment of the generalist practice and the value added of being able to help others. Responses related to the community included having a sense of belonging, enjoying the space and natural beauty of the surroundings, and the less hectic lifestyle compared to urban areas. In response to the question regarding challenges, two themes emerged: transportation, and limited resources. The lack of transportation was noted as making serving individuals difficult as was the limited resources of both the agencies as well as clients (e.g., poverty).

Conclusion: Respondents identified several reasons that they enjoy working in rural areas, particularly related to family and personal relationships, and the lifestyle and the close-knit nature of rural communities. Respondents generally reflected a feeling that the work they did was valuable. Challenges associated with limited resources to serve individuals in rural communities and the greater needs of clients (e.g., limited transportation options, greater incidence of poverty) were expressed.

Factors that Promote Rural Counselor Recruitment

In studies of rehabilitation and allied health professionals working in rural areas, researchers found several common themes related to why individuals were interested in pursuing their jobs. For those who were originally from the region, having personal or family ties was a common response. Another compelling reason was opportunity for family – including employment opportunities for spouse or partner and quality of education and opportunities for children (Daniels, VanLeit, Skipper, Sanders, & Rhyne, 2007). For those who grew up elsewhere, training on service in rural areas, exposure to working in the region through clinical internships, desire to serve an area with high need, and financial incentives for working in an underserved area were reported as encouragers to pursue rural employment (Daniels et al., 2007; Winn, Chisholm, Hummelbrunner, & Hummelbrunner, 2014). Other perceived benefits of positions in rural communities include career opportunity, challenge and autonomy, and feeling that you are doing an important job (Campbell, McAllister, & Eley, 2012). Benefits of rural living expressed by human service employees include nice living environment, relaxed lifestyle, ease of commute, friendly and welcoming community, and affordable real estate (Denham & Shaddock, 2004). The following is a discussion of strategies utilized by agencies looking to enhance recruitment, particularly recent graduates of counselor training programs.

Partnerships with Counselor Training Programs

In order to increase visibility with students training in rehabilitation services, Human Resources Directors (HRDs) might consider investing in direct and ongoing communication with university partners, considering them an important audience for community outreach (Dew, Alan, & Tomlinson, 2008). Some methods for connecting include both in-person and technology-assisted outreach to reduce the strain of travel. If feasible, have counselors visit students and programs to discuss benefits of rural employment. Open agency doors for visits, allowing students and faculty to come see the agency space and get a sense for day-to-day operations. Counselors and staff who are taking classes to obtain credentials are also good potential recruiters. Respondents to a survey of VR agencies noted that this method is used frequently and considered effective; agency staff reported filling approximately 25% of vacancies this way. As stated by one agency representative, "our people can be our best ambassadors, but they must want to be" (Dew et al., 2008, p. 66). Bishop, Crystal, and Sheppard-Jones (2003) concurred with this sentiment, stating that counselors who are committed and enjoy their work are potentially powerful recruiters.

As key partners, agencies have the opportunity and responsibility to inform training programs of the needs of the field. Sharing this information is particularly important for rural service providers whose circumstances often differ from community partners in urban and suburban areas. Findings from a study of rural allied health professionals suggested that programs that recruit applicants from rural areas and include rural services as an aspect of training have more students who pursue work in rural communities postgraduation (Daniels et al., 2007). Rural service providers can assist programs with developing rural-specific content to compliment training and serve as potential guest speakers, mentors, or resource experts for students during their studies. This ensures that trainees are getting content that reflects the realities and benefits of serving rural residents.

Given the challenges associated with building relationships over great geographical distance, utilizing technology to be present and keep in touch with educational program partners may be prudent. If it is not feasible to visit in person, making use of teleconference or video technology to be a guest speaker, participate in advisory meetings, or working one-on-one with students still allows for interaction. Video technology has the added benefit of enhancing personal interactions. When possible, investing in travel so that face-to-face meetings or visits can occur is also important.

Providing Mentored Training Opportunities

Fieldwork requirements for counselor program accreditation include both practicum and internship (Council for Accreditation of Counselor and Related Educational Programs, 2016; Council on Rehabilitation Education, 2014). Other allied health professionals also have internship, fieldwork, or clinical rotation requirements. Agencies may consider offering to host and mentor students completing these requirements as "formal channels for recruitment" (Dew et al., 2008, p. 15). In a survey of VR agencies, approximately two-thirds of survey respondents use this strategy, and 90% found it effective (Dew et al., 2008). Considering stipend or paid positions to offset travel costs incurred by student trainees, if feasible, will make this opportunity more attractive. Another possible approach is to utilize technology (see more about this approach in Chap. 34) to aid with training via distance modalities. The benefit to the agency of attracting the most qualified candidates is that you get to see the student perform in the work environment prior to offering a permanent position. Both parties get to "try out" the employment situation before a more permanent job offer is extended. This will help the agency decide if the student trainee is a good match, and help the student decide if working in this location is consistent with their career goals. However, in order for this to be a positive experience for the trainees, the agency, and the educational program, there must be a structure in place to ensure that the needs of all parties are known and addressed and that the experience is not too burdensome on the agency staff to become prohibitive.

Preparing Staff to Supervise and Mentor

Counselors and staff are likely at different levels of skill and preparation to assume supervisory and mentoring roles. New staff in particular may be focused on learning the job themselves that adding the responsibility to mentor or train a student would be detrimental to their own professional growth. For students and new staff, it is critical to have supportive, positive mentors to help acclimate and learn the professional role. Prior to taking on any students, talking with more experienced staff about the agency's capacity to take on trainees and the practicalities of doing so is essential. It is important to get information from key personnel on their interest and availability of taking on students and how they anticipate students fitting in to the day-to-day operations. This will allow for projections of what opportunities may be offered and the timeline for making them available. Agencies and university partners can work through the details together, with each understanding the needs and capacities going in to the arrangement. For staff, there is additional work involved with taking students for training, and if the specifics are not arranged beforehand, the situation can become burdensome and negative for staff, students, and clients.

In addition to the practical preparations for students, providing staff with some models of supervision and mentoring will help them be more effective when working with students. Some staff may wish to participate in student development but feel unprepared to do so. Providing some guidance on mentoring and supervision prior to introducing student trainees will increase the likelihood of a good experience for both students and staff involved in this partnership. Staff members who feel as though they are thrown into situations unprepared may feel more strained with this new kind of responsibility. Students working under staff with insufficient preparation or knowledge to provide this kind of training may have a negative experience and thus leave with a negative impression about the agency and perhaps working in rural settings on the whole.

Developmental models such as the tripartite model of supervision (Schultz, 2008), which encourage attention to clinical supervision, administrative supervision, and professional development, are applicable to rehabilitation settings and provide novice supervisors a framework with which to approach training students. Central to this approach is developing the supervisory working alliance. Many practitioners in rehabilitation settings step in to supervisory roles without the necessary knowledge or skills because of the gap in training available at the master's level in this area. Thus, having students training with the agency provides additional professional development and growth opportunities for more advanced practitioners as well as students. Students trained by staff with an understanding of counselor development and effective supervision are likely to have a better learning experience than those trained by staff without these competencies.

Meeting the Training Needs Associated with Accredited Programs

A critical point to ensure long-term success of practicum and internship programs housed by an agency is the ability of the agency to meet the requirements set by the program accreditation. Programs must place students in settings that meet the specific learning or experiential milestones associated with their requirements. For example, in counseling the accreditation bodies, both require a counseling practicum lasting at least 240 clock hours, with 40 h of direct services to clients. If the agency wants to host practicum students, they must be able to guarantee that students will receive this kind of experience. Other requirements include individual or group supervision, shadowing opportunities, and other learning objectives. Along with preparing staff to supervise and mentor students, working closely with training programs to understand the requirements and evaluate whether or not they can be fulfilled in the agency is something that must happen prior to entering into agreements with programs. Handling these requests up front puts less pressure on staff who are charged with working with students and the students who must meet the requirements in order to fulfill program criteria and graduate.

Promoting from Within

Another human resource development strategy is referred to as "grow your own" (Byham, Smith, & Paese, 2002). This strategy is based on the idea that existing staff members are prime candidates to invest in for future growth. Staff members who are currently employed have an intimate understanding of the agency purpose and mission and ideally a commitment to the work and a connection to the community. This strategy is also consistent with findings that many rehabilitation counselors are drawn to the profession because they gain experience with a rehabilitation counselor or a person with a disability, or they have a disability themselves (Bishop et al., 2003). For some, working at a disability services agency is their first introduction to the field of rehabilitation counseling. Staff members already working in these agencies know what the job is like and understand the responsibilities and the barriers faced. Human resource directors may identify staff that are performing well in their current positions and might wish to pursue additional training to take on more responsibility within the agency. Where feasible, offer incentives to reward those who take this initiative (Dew et al., 2008). This reduces the need to recruit for counselor positions from out of area that may or may not develop a commitment to the agency and community. It allows for the development of an already valued employee into this more skilled role with the correct training. This career ladder approach provides opportunities for upward mobility, which is also linked to job satisfaction and reduced turnover intentions.

Factors that Promote Rural Counselor Retention

Understanding factors that contribute to length of stay and motivation to leave are critical for agencies wishing to optimize retention of valued employees. Motivational factors are evident among various human service professionals, globally. There are a wide variety of personal, professional, and organizational factors that influence professionals to stay in their jobs or to pursue different ones. Job satisfaction, lifestyle, and professional networking contribute to job retention for rural rehabilitation and allied health professionals (Winn et al., 2014). In fact, when comparing intrinsic motivations (those derived from the work itself, e.g., my work has meaning, I have autonomy) with extrinsic motivations (those provided by the workplace, e.g., I am happy with my salary, I get enough vacation time), intrinsic values provide greater explanation of why workers stay in human service jobs (Campbell et al., 2012). Similar studies of healthcare workers' motivation to stay in jobs in rural areas found many healthcare workers are demotivated and frustrated because they are unable to satisfy their professional conscience and similar aspects related to professional ethos in pursuing their job due to inadequate or inappropriately applied human resource management tools (Mathauer & Imhoff, 2006). In a more recent study, Razee, Whittaker, Jayasuriya, Yap, and Brentnall (2012) found that social factors that influence the motivation of healthcare workers in rural areas included the local community context, gender roles and family-related issues, safety and security, and health beliefs and attitudes of patients and community leaders. Strong, supportive communities were identified as important social factor that influenced healthcare worker motivation.

Case Study

Sara is a 26-year-old woman living in Bedford County in Pennsylvania. She has lived there all her life and is raising her own family in this community. About a year ago, Sara went back to work after a few years taking care of her young children at home. She had a hard time finding employment but eventually was able to find a job with a group home serving young adults with intellectual disabilities. Sara never worked in a human service agency before and was surprised at how much she enjoys it. One thing she wishes is that she was able to provide mental health counseling to the young adults too, as she sees a real need for these services among the residents. She knows that she would need additional education and experience beyond her bachelor's degree to be qualified to be a counselor. Sara stands out among her coworkers as someone who has a lot of potential. Her employers have identified her as someone they would like to retain, as they have continual difficulty recruiting good staff to work for the agency – both in this particular home and in other programs. Sara's supervisor has talked with her about her career goals and is encouraging her to take some trainings offered by the agency as well as asked her to join some of the higher-level meetings so she can learn more about how the program works. These efforts are designed to support Sara and keep her engaged with the agency. Ideally, her supervisor would like her to pursue a master's degree so that she can take on additional responsibility and be more fulfilled in her day-to-day work. They are discussing giving her a flexible schedule so she can start taking a couple of classes at a time to work toward a master's degree in clinical rehabilitation and mental health counseling. They are looking for some resources to help her defray some of the costs.

The reason that Sara's employers are so interested in working with her to promote further training is that they also see a need for mental health treatment for their clients. However, they have struggled to hire counselors who are willing to move to Bedford. Students who graduate from programs within the state typically want to move to Philadelphia or Pittsburgh, and they have even had a few counselors come and work for 6 months to a year and then leave. This has been problematic for them and their clients. Sara has shown herself to be motivated and works well with the residents, and she also has family ties to Bedford County. It seems unlikely that if she were to get the training and assume a counselor position that she would leave for another part of the state or country.

Expectations of New Counselors in Rural Areas

The initial period of employment, especially for newer counselors, is stressful and comes with a steep learning curve. Pre-service counselors (e.g., students) have expectations related to what they learned in their training programs, which may or may not reflect the realities of practice. Aside from clinical experiences of practicum and internship, they may come with limited exposure to community settings. The initial period of independent practice is a major stage of professional and personal growth for new counselors, and the challenges associated with rural practice compound this growth tremendously. Agencies who hire new graduates are setting the stage for counselors, introducing them to professional expectations, decision-making, and ethics and how to balance multiple priorities at once. Their interactions with supervisors, mentors, cooperating professionals, and clients have the potential to motivate them to continue in this profession or make them question this decision. Several aspects of rural practice can support or hinder counselor satisfaction and retention over the long term. Often, the first step in the hiring process is to identify rural practitioners who are committed to living and/or working in rural settings. The following is a discussion of several of these factors, such as how agencies orient new staff to organizational culture, what aspects of the employee and the work setting support job satisfaction, and how supervisors and managers can support counselor retention.

Consistency with Organizational Culture

Organizational culture has been defined as "the basic assumptions and beliefs that are shared by members of an organization, that operate unconsciously, and that define in a basic 'taken-for-granted' fashion an organization's view of itself and its environment. These assumptions and beliefs are learned responses to a group's problems" (Swanson & Holton, 2001, p. 271). When newly hired staff members have personal values and motivations that are consistent with agency mission and goals related to client service and other shared beliefs, there is a positive impact on retention (Chan, 2003). While some information is learned and evaluated during the job search, application, and interview process, the initial period of employment is when new hires are truly exposed to agency culture and get the chance to see how day-to-day activities contribute and align. The degree to which the expectations of the counselors are consistent with role/responsibilities and agency culture contributes, to some extent, job satisfaction. A challenge for many agencies is moderating this adjustment. One issue that becomes particularly evident in rehabilitation agencies is performance outcome assessment. Efforts to quantify counseling performance using a single indicator (such as number of employed customers) may cause cynicism and job dissatisfaction even among those who have a strong desire to stay with the profession (Dew et al., 2008). For rural providers, greater challenges to services such as reduced access to resources, reduced employment opportunities, transportation barriers, and poverty make it even more important to have consistent alignment between new hires expectations, agency culture, day-to-day responsibilities, and methods of evaluation.

One approach that helps support staff intrinsic motivation to stay is to communicate with staff on a regular basis and highlight how their efforts contribute to the overall goal. Agencies may engage in what is often referred to as "internal marketing" to make sure that staff get info about the agency mission and goals/supporting activities the same way that external partners are informed. This helps new hires acclimate to culture and reinforces that the agency does work that is consistent with their own reasons for entering the profession. It is also important to collect information from staff, either formally or informally, to ensure that problems, questions, or issues can be addressed in a timely manner.

Promoting Job Satisfaction of Rural Counselors

Studies of rural providers have indicated that the first 12 months of employment are the optimal time to introduce retention strategies with rural employees (Chisholm et al., 2011). While the work of a rehabilitation professional is challenging (in any area), enhancing job satisfaction is an effective way to retain employees. Since each of us has our own priorities for jobs and what is important to us, there is no "one-size-fits-all" approach to retaining staff. Multifaceted approaches that address several factors related to job satisfaction are recommended. The following is a presentation of factors and strategies that promote job satisfaction related to the employee, the work environment, and the role of supervisors and management.

Worker Factors

Given the particular challenges and realities associated with rural practice, some person characteristics have been associated with more successful and greater enjoyment of the work in the long term. Successful rural practitioners as those who are creative, well trained, and can work well independently with limited additional resources (Chipp et al., 2011; Sidwell et al., 2006). These traits are particularly important for rural practitioners who are working with limited in-person supervision and without some of the resources (e.g., supportive services, multidisciplinary teams) found more commonly in populated regions. Other important traits have been identified that have greater impact on whether an individual can become integrated into the community, including commitment to the community, ability to thrive in small town life (relative isolation), understanding of how factors in cases are affected by and affect the larger community, and an understanding of rural ways of life. These personality characteristics will aid new practitioners in getting to know residents and relating to them within the rural cultural context. A person who desires to become a member of the community themselves has a greater likelihood of being accepted than one who does not embrace rural living. On a clinical note, efficient and confident assessment skills, patience, flexibility, creativity, and adaptability are all desirable. Counselors may need to practice more as a generalist and find creative solutions to client barriers within the context of limited resources. Another important area to consider is self-care. Knowing when to take a break and realizing that one person cannot address the needs of an entire community is key. Finally, for those working in relative independence, it is important to find professional consultation and supervision to support ethical and professional practice. These traits are similar to those described in other works on rural resilience and are inherently necessary when dealing with some of the challenges associated with rural practice.

Recommendations for rural providers on how to become a trusted partner in the community include methods designed to get to know residents and learn about the community. Chipp et al. (2011) suggested that providers need to work to build trust with community members, and one way to accomplish this is to get to know elders and respected residents who can help them understand the community and needs better. Another suggestion was to find a professional mentor within the area. This will in turn result in gaining the respect of others. Authors cautioned new practitioners against isolating, recommending they spend time in the community (attending church, going to market, volunteering, attending community events) and get to know their neighbors. Those who isolate are often rejected, as this goes against the value of being social and neighborly that is often shared in rural communities. Relationships develop over time, so patience is required. In some cases, a provider may have to repair mistrust from past providers who have since moved on.

Work Environment Factors

Research on stress, strain, and turnover intentions has suggested that stress is ubiquitous in rehabilitation counseling positions (Layne et al., 2004). Knowing that stress and strain in rural practice may be compounded by additional barriers related to resources, work conditions, isolation, and increased barriers among residents, managing the work environment to ameliorate these issue to the extent possible may reduce turnover and increase job retention among valued staff. Several aspects of the work environment have been linked to job satisfaction and turnover in studies of rehabilitation counselors and related professionals. Armstrong et al. (2008) found that satisfaction and intention to quit significantly predicted by pay and size of caseload in VR settings. Respondents in this study were least satisfied with opportunities for promotion and pay. Pay and opportunities for growth are consistently identified issues in the human services field more broadly.

In a study of rural allied health professionals working with individuals with intellectual disabilities, Denham and Shaddock (2004) found that stated reasons for leaving among former employees included several addressable issues in the workplace. These included unfilled positions, insufficient support from peers, feeling that work was not valued by clients and managers, insufficient resources and management support, and insufficient supervision. While agencies are under constant pressures to maintain staff and recruit for positions when vacated, understanding these environmental factors that contributed to employee turnover are important to understand in order to address turnover issues. Conversely, employees reported aspects of the work environment that contributed to their satisfaction and intentions to remain, including nice living environment, helpful team members, supportive management, relaxed lifestyle, independent work, ease of commute, friendly and welcoming community, and affordable real estate. Another common theme was the importance of advancement opportunities; some staff reported leaving because organizations are too flat, there was no way to move up. This is particularly problematic in smaller agencies serving rural areas.

In a study of rural social workers, Sidwell et al. (2006) revealed several environmental contributors to job satisfaction. Respondents highlighted the favorable living conditions and community attachment as bringing joy to their work. Several stressors were also mentioned, including the lack of resources, transportation struggles, and poverty that clients experienced.

Some reported strain associated with taking on more responsibilities than one would need to in a more populated area where there are greater resources; responses included descriptions of being “tapped” for after-hours work more often and feeling overburdened by the responsibility (Sidwell, et al., 2006). The existence of dual relationships in small communities adds to the stress of maintaining professional and ethical boundaries with clients (Chipp et al., 2011).

Role of Supervisors and Managers

Managers and supervisors have a strong role in supporting the practice and job satisfaction of their employees. While some management practices are not feasible or reasonable given the setting, there are several methods identified that contribute to job satisfaction and increase likelihood of retention. One important approach is to take time to recognize and acknowledge effort, success, and effective practice (above and beyond just what is measured in performance reviews). While managers may not be able to pay bonuses, one can respond to success with praise and recognition. If possible, agencies should consider providing salary increases with credentials (e.g., MA degree, CRC, licensure). Among staff, be aware of and pay attention to generational differences as patterns of turnover may differ (Lu & Gursoy, 2016); for example, technology and teamwork are generally more attractive to millennials (Dew et al., 2008). Allow for counselor autonomy in situations where the person is qualified and demonstrates necessary knowledge and skill. Create an environment that allows staff to incorporate tasks and responsibilities that are intrinsically motivating where consistent with agency goals and mission. Aside from the payment of bonuses or higher wages, many of these approaches are free of cost or cost very little to implement.

A consistent theme noted in the job satisfaction literature in rehabilitation and human services is that employees appreciate when their employers support continued professional growth. Another management practice that supports retention is to provide opportunities for professional development and growth – for example, training, networking, and involving staff in higher-level initiatives/workgroups. While participating in these additional activities may seem to come at a cost to current responsibilities, do not shield staff from these types of opportunities in an effort to not overburden them (Dew et al., 2008, p. 114). Instead, try to take the pressure off of staff so that they are free to participate within reason.

Many healthcare providers and related professionals such as rehabilitation counselors are trained in an urban-centric model of care. They come to expect and depend on resources that may not be available in rural locales, meaning that they come in insufficiently prepared to practice within the rural context. Especially for those who come in unprepared, not having adequate supervision, training, and continuing education contributes to burnout and turnover (Chipp et al., 2011). For managers and supervisors, understanding your staff, their preparation, strengths, and gaps in training is important to structure their initial time to fill these weaknesses. Pairing new staff with more experienced staff, carving out time for them to get to know available community resources, and ensuring supervision time are all methods of helping new counselors get up to speed once they start working in your agency.

For all staff, participating in what is termed *responsive management* can increase job satisfaction and staff retention. Responsive managers listen to counselor and staff concerns and include counselors/staff in the process of decision-making and future planning. In some situations, nothing can be done to ameliorate the problem or change the circumstance; however, this does not mean that staff cannot understand these competing priorities when included in the discussion. When changes cannot be made, transparency about the process, the reasons, and identifying possible alternative approaches is helpful to keep the relationship between managers and staff intact.

Discussion Box 35.1

Agency X has approximately 13 locations in the Upper Peninsula of Michigan and serves persons with mental health, developmental, and substance-related disabilities. The locations are spread between 1 and 2 h driving time from each other, and service areas have been carved out to reduce the travel burden on staff to the extent possible. Staff at the Escanaba location typically covers about 30–45 min north, east, and west of the office. Each counselor has a caseload of about 15 clients and is out of the office most days, only stopping in for staff meetings, case management, and other administrative tasks.

Discussion questions:

1. How might the agency organize counselors and supervisors to ensure that counselors are supported in their work and sufficient risk management practices are in place regarding availability and quality of supervision?
2. How could the agency provide training and continuing education to counselors who are rarely in the office?
3. What distance-supported or electronic means could the agency use to allow greater communication in real time when needed?

Agency Assessment of Strengths and Weaknesses

Very few human service organizations operate without any oversight or compliance responsibilities. Most are required to participate in some kind of strategic planning, program evaluation, and/or quality assurance exercise on a regular basis, to evaluate and track overall effectiveness of services (IRI, 2011). Management can take several approaches to these mandates, ranging from full participation and commitment to quality improvement to an approach of meeting the requirements because they must be met but expressing skepticism and resistance to change (Morris & Ogden, 2011). Staff members are excellent contributors to assessment of agency strengths and weaknesses, as well as a critical audience for evaluation results. Particularly in agencies where many staff are located off-site in the community or spread out to satellite offices, they are typically most informed about day-to-day challenges and victories. Organizations may use internal review procedures (e.g., case files, case notes, observation) to identify areas of training needs for staff. Ensuring that communication flows both ways (e.g., from managers to staff and from staff to managers) is critical to collecting information on agency functioning, effectiveness, and future needs including training (Fleming, Boeltzig, Foley, Halliday, & Burns, 2014). Responsiveness to unmet needs, gaps in infrastructure, and areas of inconsistency with agency mission sends a strong message to staff regarding the culture of the organization: is this a strong organization with a vision that matches day-to-day responsibilities? These messages have an impact on staff retention.

Future Implications

The need for qualified professionals practicing in rural areas is not going away; in fact, the opposite is more likely. Several outside influences have bearing on recruitment and retention picture; such as mandates on client to staff ratio, reimbursement tied to staff qualifications, and other requirements related to having a particular number of staff with specific educational or experience requirements (Morris & Ogden, 2011). Educational programs, particularly those in states with rural and frontier areas, need to consider rural culture and practice as part of the curriculum (Breen & Drew, 2012), covering issues such as ethical considerations, working in isolation with few resources, and seeking supervision and consultation at a distance. Service agencies in rural areas may also consider the value of partnering with counselor preparation programs in order to enhance the qualifications of existing staff to meet the needs of their clients and accreditors and/or funders.

Summary and Conclusions

Human service agencies rely heavily on staff to provide effective and ethical services to clients. In rural areas, noted problems with recruitment and retention of qualified staff have impacted services in rehabilitation counseling, as well as related social work and allied health disciplines. Addressing this gap requires a multifaceted approach and the work of several partners. Agencies, training programs, and counselors all have a role in addressing staffing issues. From the training side, educational programs need to include greater attention to rural issues, including providing information and experiences to students in order to encourage them to consider rural areas as a potential place to develop a career. This is particularly important for educational programs that are located in states with a significant rural populous. Agencies may consider strategic recruiting and retention efforts, such as promoting staff from within, partnering with educational programs as clinical sites, and encouraging applications from potential staff who demonstrate a desire to live in the area where services are provided. From the retention side, working with staff to keep qualified and effective practitioners reduces the burdens associated with turnover is critical; supervisors and managers play a significant role in addressing staff needs. Management practices that are responsive to staff issues and maintain communication and transparency are recommended to increase satisfaction and retention over time. The benefits extend past retention, as satisfied staff members are effective recruiters.

Resources

1. Occupational Outlook Handbook- US Department of Labor: http://www.bls.gov/ooh/
2. Rural Health Information Hub: Recruitment and Retention Strategies: http://www.ruralhealth.va.gov/docs/issue-briefs/rural-provider-retention.pdf
3. National Career Development Organization: http://www.ncda.org/aws/NCDA/pt/sp/resources

Learning Exercises
Self-Check Questions

1. Explain the "costs" associated with high levels of counselor turnover: include a discussion of the financial and human consequences, to the agency, coworkers, clients, and community.
2. Consider your own preferences: what are your top three priorities when it comes to a job that you would consider ideal? What would make you want to stay with an agency or company for a significant period of time?
3. What aspects of a work environment or culture do you think contribute to employee dissatisfaction or turnover?
4. Identify three things that you think managers or supervisors could do that would improve employee satisfaction.
5. If you were recruiting counselors for a rural agency, what kind of person would you be looking for?

Field-Based Experiential Assignments

1. Look up three human services agencies in your local area. Visit the website to find (or call if not available) information on recruitment initiatives, employee benefits, and retention programs.
2. Interview three people you know to find out what attracts them to jobs and/or companies, what is important to them when considering possible career moves, and what makes them want to stay in a position for a significant period of time.
3. Do a labor market analysis of your local area: find out what rehabilitation and counseling jobs are available, pay ranges, and desirable qualifications.

Multiple Choice Questions

1. Which trend is evident in rural areas with respect to staffing?
   (a) Inexperienced professionals begin their careers in rural areas and then leave.
   (b) More experienced professionals move to rural areas when they get closer to retirement.
   (c) Rural areas have much fewer problems with recruitment.
   (d) There is no trend observed related to staffing.
2. Individuals who _______________ are more likely to seek employment in rural settings.
   (a) Were raised in cities.
   (b) Dislike rural areas.
   (c) Gain experience in rural areas.
   (d) Are open to new experiences.
3. Some of the perceived benefits of working in rural communities are:
   (a) The pay is higher.
   (b) Less travel is required.
   (c) Affordable living.
   (d) The work is easier.
4. One limitation noted in educational programs that hurts rural recruitment is:
   (a) Instructors discourage students from applying.
   (b) Limited discussion of rural content leaves students unprepared.
   (c) Most guest speakers come from rural areas.
   (d) Too many students are from rural areas.
5. _______________ has been identified as a "formal channel for recruitment."
   (a) Agency-sponsored job fairs held in rural locales
   (b) Promoting counselors to supervisor roles immediately
   (c) Hosting students for clinical practicum or internship
   (d) None of these
6. Counselor ____________ has been shown to impact client satisfaction.
   (a) Job satisfaction
   (b) Preferences
   (c) Similarity of hobbies
   (d) Shared culture
7. An example of an intrinsic motivation to stay in a professional job is:
   (a) A high enough salary.
   (b) Sufficient vacation time.
   (c) I like my coworkers.
   (d) My work is personally meaningful.
8. An example of an extrinsic motivation for retaining a professional job is:
   (a) I feel that my work has value.
   (b) I feel fulfilled by my contributions.
   (c) The benefits are generous.
   (d) I have autonomy.
9. A new practitioner working in an unfamiliar area may consider ___________ to become more integrated into the community:
   (a) Volunteering
   (b) Attending community events
   (c) Joining community groups
   (d) All of these
10. Responsive management is best defined as:
   (a) The process of listening to staff concerns and including staff in decision-making and planning
   (b) Protecting staff by not letting them know of agency challenges and concerns
   (c) Always doing what staff ask
   (d) Simplifying daily tasks so that staff do not have to work so hard

Key

1. A
2. C
3. C
4. B
5. C
6. A
7. D
8. C
9. D
10. A

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Capacity Building in Rural Communities Through Community-Based Collaborative Partnerships

Kathy Sheppard-Jones, Elizabeth Hunter, and Walter Bower

Overview

The importance of collaboration in human service systems cannot be underemphasized for persons with disabilities, particularly within the current economic context in which budgets are more constrained and smaller numbers of personnel are responsible for larger scopes of work. When taking a holistic view of a person, it is also important to recognize that a situation may not require only one intervention, but a variety of techniques to positively influence outcomes. Collaboration is defined as working together to create or accomplish something. Collaborative partnerships are essential in rural service delivery. In this chapter, we will explore the benefits and challenges to rural collaboration and explore a variety of rural partnerships that maximize outcomes for rural residents with disabilities.

Learning Objectives

Upon completion of this chapter, the reader should be able to:

1. Identify collaboration and interagency collaboration
2. Recognize why collaboration is important in rural settings
3. Identify elements of good collaborative partnerships in rural rehabilitation
4. Recognize barriers to collaboration in rural partnerships
5. Describe models of successful collaborative relationships for people in rural areas
6. Develop strategies to identify and develop collaborative efforts for rural residents

Rural Communities

Rural communities have served as the foundation of our country. Through our nation's history, the rural life has nourished and sustained the nation. Rural communities offer unique assets and strengths as diverse as the people who reside within them. However, rehabilitation professionals recognize that there are challenges associated with providing quality services to rural community members with disabilities. It is well recognized that people residing in rural areas may experience greater economic, social, and health disparities while having access to fewer local resources (Kuipers, Kendall, & Hancock, 2001). Rural community members living with any kind of disability can be faced with multiple problems that make the

K. Sheppard-Jones (✉) • W. Bower
University of Kentucky, Human Development Institute, Lexington, KY, USA
e-mail: kjone@uky.edu; walt.bower@uky.edu

E. Hunter
Graduate Center for Gerontology, University of Kentucky, Lexington, KY, USA
e-mail: eghunt2@uky.edu

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disability harder to manage and live with. The nature of rural communities, and lack of access to specialized care and resources, can result in this population being underserved. This can negatively impact quality of life, health outcomes, and full participation in life. A thorough understanding of how to collaborate with formal and informal entities can aid in positive outcomes at the individual level and build capacity across systems. In this chapter, we will first define collaboration and describe the importance of establishing and sustaining community partnerships. We will discuss some of the barriers that may exist when serving those in rural areas. We will also explore mechanisms for developing collaborative opportunities and show an example of multi-stakeholder collaborative in Appalachian Kentucky that has engaged interdisciplinary professionals, community members, people with disabilities, and their family members. Finally, we will offer suggested ways for rehabilitation professionals and administrators to navigate the rural landscape, across agencies, across community-based assets, and across disciplines to enhance outcomes for consumers of rehabilitation services.

Some examples of potential professional collaborators in rural rehabilitation are:

- State vocational rehabilitation agencies
- Centers for Independent Living (CIL)
- Public health departments
- Community mental health centers/social services
- School districts
- Cooperative Extension Systems
- Local colleges or technical schools

Within each of the above are a cadre of professionals who can provide particular expertise. However, it is also important to remember that collaborative partners do not only consist of professional providers of rehabilitation services. Powerful collaborators can also include:

- Community leaders
- Church leaders
- Community members with a variety of backgrounds who are connected to the individual with a disability

Collaboration

Collaboration occurs when two or more people work together to accomplish a task. More formal collaborations between people from different organizations who are working toward a shared goal are referred to as *interagency collaborations*. Collaborations in which "two or more stakeholders pool together resources in order to meet objectives that neither could meet individually" (Graham & Barter, 1999, p. 7) have the potential to greatly improve outcomes for rural populations. In times when budgets are shrinking and job tasks expanding, the opportunity to pool knowledge, ideas, and workloads can enhance efficiency and lead to better resolution for people who are utilizing rural rehabilitation services and supports.

Community Partnerships

In rural communities, *community partnerships* are essential in service provision. Community partners assume shared responsibility for agreed upon goals. The partners consist of collaborators who work together positively and productively. The inherent benefits of collaboration include using the strengths of cross-disciplinary knowledge to better solve complex problems, utilizing group ideas, and brainstorming to propose solutions that may not have been thought of (or possible) when approached by a single rehabilitation professional, providing services more efficiently and with less redundancy, and by bringing together more resources that can improve outcomes.

Rehabilitation professionals can use person-centered planning tools when collaborative partnerships are being established to work with individual cases. One example of such a tool is the relationship map. Relationship maps are important resources that can identify people who serve as informal or formal supports to the person with a disability. The identified people may be family, friends, and service providers or represent other community organizations. This effort as defined by O'Brien (1992) will help to determine the community opportunities that may already exist to assist the person with a disability in achieving his or her goals and pursue interests. In rural communities, an understanding of the existing community entities can vastly improve collaborative possibilities. Below are descriptions of some potential community partners.

Potential Community Partners

Faith-Based Organizations These are churches, synagogues, mosques, and other organized religious or spiritual groups. In rural communities where resources can be scarce, a person's religious community can provide a variety of supports. While these organizations are grouped together based on faith, they also bring the respective networks of their collective members, thus potentially opening up previously untapped possible vocational or independent living options available within the immediate community.

Cooperative Extension System The Cooperative Extension System has a presence in every state in the nation. While every county no longer has an extension office, regional offices support rural communities, providing research-based information to community members and professionals around family and home, agriculture and food, community economic development, and youth. Of particular interest to the rehabilitation field is Extension's focus on reduction of poverty and youth transition. As will be detailed later in this chapter, Cooperative Extension is also connected with the AgrAbility program. Further exploration of this collaboration will be discussed later in this chapter.

Positive collaborative relationships do not happen by accident. They involve people who are:

- Good communicators
- Proactive
- Persistent with follow through
- Respectful to all parties
- Able to learn from setbacks as well as from successes

These characteristics are true for all collaborating parties, whether they be considered a professional or a person of significance to the individual who is receiving services. Each person must be willing to balance power and control and to use the overall goals of the collaboration to drive the work that is being done.

Barriers to Collaboration

Unfortunately, a variety of disincentives to collaboration exist. Inherent barriers to collaboration can happen when organizations have differing:

- Missions
- Structures
- Priorities
- Funding sources
- Levels of support from leadership
- Schedules
- Professional disciplines

There is no real benefit to including an organization as a collaborative partner if that participation is not real and meaningful. To simply include Agency X for the sake of being able to say that entity is involved brings nothing to the collaboration. In fact, it can damage professional relationships by disenfranchising Agency X who is not genuinely needed or included. This can lead to even bigger problems down the road, when a situation arises in which the expertise of Agency X would be beneficial. Determining who the right people are to have at the table is critical. This is also why is it good to recognize that collaborative partnerships may evolve over time. Contacts that did not develop initially may evolve over a longer period of time into a strong collaborative partnership. It may be discovered that a Center for Independent Living has valuable money management training and referrals for home modifications for a particular case and that they are subsequently "on call" for future needs of a consumer.

Capacity Building

In order to maximize positive working relationships across organizations and ensure the focus of efforts is centered on the person with a disability and the family, Walter and Petr (2000) outlined the elements for success as including:

- Missions that recognize family-centered principles
- Involvement of community members and families
- Accountability
- Emphasis on person-centered decision-making
- Emphasis on linkages of informal supports

In all communities, but rural in particular, capacity building is one method to help fill potential gaps in services through community-based collaborative partnerships. Capacity building is a conceptual approach to development that focuses on understanding the obstacles that inhibit people, governments, international organizations, and nongovernmental organizations from realizing their developmental goals while enhancing the abilities that will allow them to achieve measurable and sustainable results.

The steps for capacity building include:

1. Engaging stakeholders on capacity development
2. Assessing capacity needs and assets
3. Formulating a capacity development response
4. Implementing a capacity development response
5. Evaluating capacity development

There are multiple levels of capacity from the individual to societal level. The individual level requires the development of conditions that allow individual participants to build and enhance existing knowledge and skills. It also calls for the establishment of conditions that will allow individuals to engage in the process of learning and adapting to change. The institutional level involves aiding preexisting institutions. It should not involve creating new institutions, but rather modernizing existing institutions and supporting them in forming sound policies, organizational structures, and effective methods of management and revenue control. Finally, the societal level should support the establishment of a more interactive public administration that learns equally from its actions and from feedback it receives from the population at large.

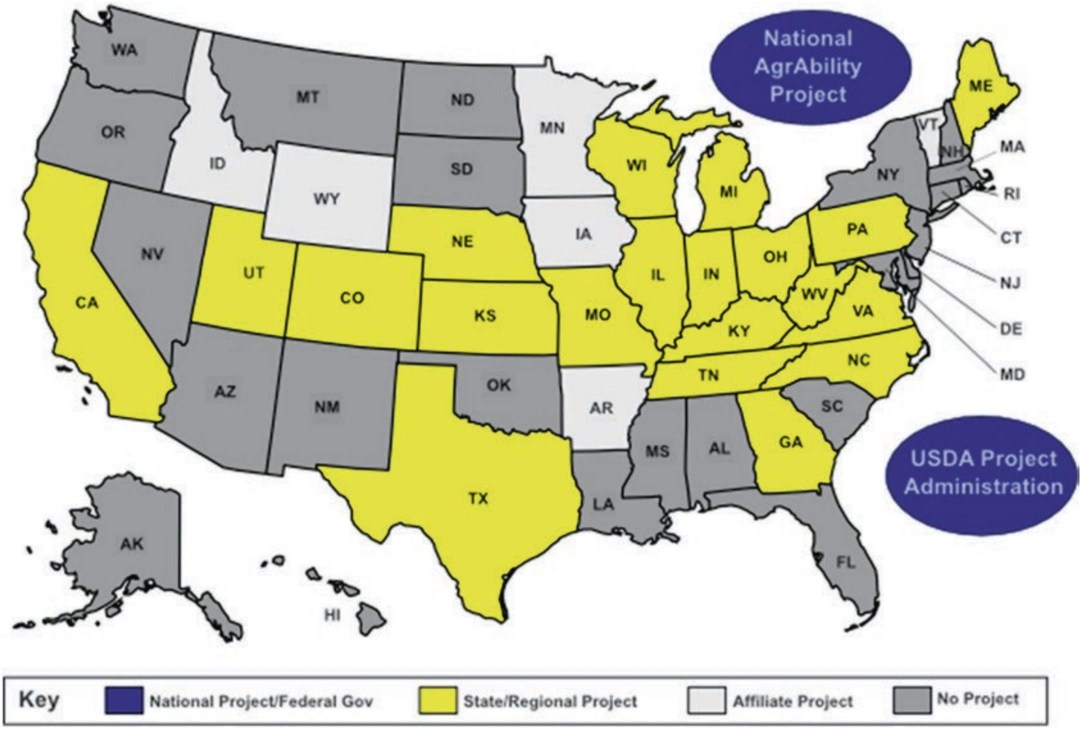
There are two ways to quickly build capacity: (a) develop a new program or service based on the prioritized needs of the collaborative group, or (b) connect with existing resources. In this chapter, we will give examples of these two types of capacity building partnerships. AgrAbility represents an effective capacity building mechanism that has existed since 1990 in many states around the country. The Kentucky Appalachian Rural Rehabilitation Network (KARRN) is a unique rural collaborative that grew from research to address the needs of constituents in rural Appalachia.

The National AgrAbility Project

One example of long-standing collaborative partnerships in rural communities can be found in the AgrAbility program. AgrAbility is a program administered by the National Institute of Food and Agriculture (NIFA) and sponsored by the US Department of Agriculture (USDA) to serve farmers with disabilities and their families affected by disability so they can continue to have successful agricultural careers. The program provides training, education, and assistance for the rehabilitation of farmers, ranchers, and agricultural workers who have been affected by physical, cognitive, or illness-related disabilities (Mathew, Field, & Etheridge, 2011). With an increasingly older rural and farm population, the need for the services AgrAbility provides to agricultural workers with disabilities is expected to grow as well.

AgrAbility was initiated through the Farm Bill of 1990. The following year, eight state AgrAbility projects were funded. In 1991, the National AgrAbility Project (NAP) was established to coordinate the state AgrAbility projects and was administered through the Breaking New Ground Resource Center at Purdue University in West Lafayette, Indiana, in partnership with Easterseals. By 2000, the number of state AgrAbility projects had expanded to 18. In that same year, the administration for the NAP relocated to the University of Wisconsin-Madison and continued the partnership with Easterseals ("History of AgrAbility," 2016).

In 2008, the National AgrAbility Project returned to Purdue University partnering with Goodwill Industries International, the Arthritis Foundation-Indiana Chapter, and the University of Illinois Urbana-Champaign. Prior to the inception of AgrAbility, the Breaking New Ground Resource Center in Purdue's Department of Agricultural and Biological Engineering had been providing services and information for the rehabilitation of individuals working in agriculture since 1979. In addition, Vermont and Iowa had programs that assisted farmers with disabilities previous to the establishment of AgrAbility. Currently, 26 states have projects or are affiliates of the AgrAbility program, with each program hosted by a designated land-grant university ("History of AgrAbility," 2016).



The National AgrAbility Project (NAP), with an annual budget of 4.2 million dollars, consists of a national network of state AgrAbility programs. NAP provides services and information to farmers with disabilities and their families including educational training to increase the professional development of AgrAbility staff and promote the autonomy of AgrAbility clients, networking to facilitate the efficacy and capacity building of agricultural disability networks, and direct service provision through individual assessments to agricultural workers with disabilities.

The state-level AgrAbility projects, also funded by the USDA, are administered through a collaborative partnership. The partners must, at a minimum, include a land-grant university who works in concert with a nonprofit organization in the state, such as Easterseals, Goodwill Industries International, an Arthritis Foundation affiliate, or Center for Independent Living (CIL). The state programs have their own professional staff who work to support the goals of the program (Mathew et al., 2011). Each statewide program provides a core set of services that include identifying assistive technology for agricultural equipment, modifying agricultural operations, assessing agricultural work sites, and distributing information on safe farming practices to farmers with disabilities. AgrAbility projects also work to connect farm families with disabilities to each other, recognizing the importance of peer support and networking in providing ongoing support for farmers.

Although not intended to provide direct payment or equipment to help farmers, the state AgrAbility programs function as an intermediary to work with other sources of funding, such as Vocational Rehabilitation (VR) Services, to assist farmers who want to continue agricultural work after the onset of a disability (Haire, 2007). A recent evaluation of the impact of the National AgrAbility Project from one study demonstrates the overwhelming majority (88%) of AgrAbility clients are able to continue to engage in full-time or part-time farming after the onset of their disability (Meyer & Fetsch, 2006).

Approximately 500,000 persons working in agriculture have physical disabilities that interfere with their performance of essential tasks. For this target audience, "success" may be defined by many parameters, including gainful employment in production agriculture or a related occupation, access to appropriate assistive technology needed for work and daily living activities, evidence-based information related to the treatment and rehabilitation of disabling conditions, and targeted support for family caregivers of AgrAbility customers. AgrAbility addresses a wide variety of disabilities. AgrAbility represents unique partnership opportunities via Cooperative Extension and state disability organizations. This collaborative partnership shows the power of harnessing entities with very differing areas of expertise, allowing both to maximize efforts and improve outcomes for the consumer. It is important to note that AgrAbility projects do not provide funding to farmers. However, this program provides an opportunity to develop additional collaborations, depending on the needs of the individual. For example, state rehabilitation agencies may work in tandem with AgrAbility to provide needed assistive technology to maintain employment and independent living. Other organizations can be sought out for nonemployment-related needs to maintain way of life.

Kentucky AgrAbility Case Study

As with the National Project, Kentucky AgrAbility has a threefold mission: professional training, technical assistance, and information dissemination. Kentucky AgrAbility has a long tradition of providing extensive direct on-farm technical assistance. In this capacity, they make recommendations related to modifying/adapting tools, equipment, machinery, and farm tasks. They also help educate on how to make the home and farm building more accessible. Kentucky AgrAbility has a strong partnership with the State Office of Vocational Rehabilitation. For appropriate farmers, vocational rehabilitation can join the process and provide training and equipment that help keep these farmers farming.

Background

Jack is a 65-year-old male with a left below-the-knee amputation as of February 4, 2011, as a result of diabetes. He has his second prosthesis that he says is fitting "pretty well." Jack has a cardiac history and has had stents placed. Jack also has arthritis with back pain. Jack and his wife Gina are directors of Internet sales for a local stockyard. Jack and his wife live in a two-story home on 5 acres where they manage 2 horses, a donkey, 18 lambs, and 10 ewes that they feed twice a day. The county extension agent recommended Jack contact someone regarding the AgrAbility program.

Challenges Identified During Visit

When asking Jack what he felt he needed help with in the operation of his farm activities, he said "nothing that I know of right now but that I may need something I am not even aware of." He was very pleasant and willing to share information on the activities and operation of his farm. He was open to suggestions that could assist him in the daily activities on the farm.

Functional Assessment

Jack walks from the house to his barn, pasture, and utility shed with a cane, but he did not use a cane on the date of visit. The distance to each of these areas is approximately 150–300 feet of grass and gravel terrain with slope and uneven terrain. Jack walked with a slow labored gait, having to laterally weight shift further to advance prosthesis. Jack showed shortness of breath after walking from house to the pasture beside house, then to the barn and utility shed. Jack demonstrated his path through the barn where he opened metal gates to enter stalls where the sheep are sheered and access to back pasture where the sheep reside. To feed his animals, he fills a bucket from the barn and carries it approximately 30 ft where he lifts it over the fence to pour it in the trough. The buckets weigh approximately 5–10 pounds. When walking from barn to utility shed, Jack showed slight imbalance on two occasions with uneven terrain but was able to self-correct. He showed shortness of breath with each distance. When asked if he experienced any pain with his activities, he stated that after 30–40 min of walking, he has pain in the lower back and left residual limb. He has a garden tractor with a garden cart attachment and a zero-turn mower. The garden tractor is located in the barn, and the zero-turn mower is located in the utility shed. Jack had not been on his mower since his amputation but did so with contact guard from this occupational therapist. This transition would not be safe for him without someone to assist as he appeared slightly unsteady when stepping on to mower.

Inside Home

When asked if he had difficulty accessing areas inside his home, he said no not really. After offering to look over areas in his home to give suggestions for ease and safety, Jack took us through his home while describing his adaptations and modifications already made. There were several areas that could improve his mobility and safety in the home that were discussed during the visit:

Stairway – Four steps to a landing then long stairway to second floor where there is only one railing. Recommended railing on both sides since it was narrow enough to reach both sides simultaneously. Rail on both sides will provide improved muscle power, energy conservation, weight shift, joint protection, and safety while ambulating stairs which he does several times a day.

Bathroom – The door way is narrow making it difficult for access via wheelchair which he uses to transition to shower chair. He has wheelchair on both levels of home. Shower stall is narrow where he has a small shower chair that he transitions to after removing prosthesis. Recommended transitioning to shower chair with prosthesis on for increased stability then removing once seated on shower chair. His commode is standard height with small grab bar on one side. Recommended elevated commode with bilateral grab bars on each side to improve muscle power, joint protection, and body mechanics and conserve energy.

Safety Implications

Safety concerns include uneven terrain that can create potential for falls when walking from house to barn and utility shed. Carrying feed buckets to trough on uneven terrain 30 plus feet poses a potential to increase back pain and compromise right leg and hips due to increased demand. Lack of railing on stairs inside home puts Jack at risk for increased back pain and joint compromise with muscle imbalance with postural compensation to manage steps several times a day. His compensation requires increased energy which creates increased shortness of breath. Standard height commode and small shower stall increase risk of accelerated joint wear and pain with potential for falls with transitions.

Action Plan

Share findings with AgrAbility team to determine recommendations for modifications and resources that will increase Jack's safety and accessibility while managing his farm activities. Provide Jack with joint protection, energy conservation, and work simplification strategies to assist in self-care and farm management. Provide Jack with contact information for resources to assist with modifications.

Questions:

1. Who should be members of Jack's rehabilitation team?
2. What other needs can you identify that should be included in an action plan?
3. Are any of these needs related to community participation or quality of life?

Kentucky AgrAbility's involvement as a collaborative partner and member of Kentucky Appalachian Rural Rehabilitation Network, described below, is an example of building capacity by connecting two existing collaborative resources. The services provided by AgrAbility benefit KARRN and the community members who access the resources KARRN provides, and KARRN provided a way for Kentucky AgrAbility to expand services in the underserved region of Appalachian Kentucky. This was a win-win partnership and a sound example of building capacity to serve communities. It also shows that collaborative partnerships, even among groups with strong internal collaborations, are better together.

Kentucky Appalachian Rural Rehabilitation Network (KARRN)

Of the 420 counties that comprise Appalachia, those located in eastern Kentucky are among the poorest. Approximately 80% of these Kentucky counties have a shortage of designated health professionals and healthcare resources to address life changing injuries/illnesses. The Kentucky Appalachian Rural Rehabilitation Network (KARRN) has been established as a collaborative team including individuals with spinal cord injury (SCI), stroke, and traumatic brain injury (TBI), providers who serve them, members of communities in which they live, advocates, educators, and researchers who investigate these impairments. The goal of KARRN is to identify, develop and disseminate information and strategies, and maximize resources to improve health outcomes and quality of life for individuals with neurologic conditions living in rural Kentucky Appalachian counties.

Initial funding for KARRN was through a research grant by the Experimental Program to Stimulate Competitive Research (EPSCoR; funded through the National Science Foundation). The initial study examined the health and quality-of-life-related supports and challenges from the perspective of individuals with spinal cord injury (SCI) and their families and from the healthcare providers who treat these individuals. Additional funding was provided by the National Institutes of Health and National Center on Minority Health and Health Disparities. The additional funding allowed for the broadening of focus from SCI to include stroke and TBI. It also provided the funding to develop infrastructure to help solidify the network through a telehealth system and annual conferences.

KARRN was developed as an outcome of the community-based participatory research (CBPR) approach. CBPR is a collaborative research process involving researchers and community representatives; it engages community members, employs local knowledge in the understanding of health problems and the design of interventions, and invests community members in the processes and products of research (Cornwall & Jewkes, 1995). In addition, community members are invested in the dissemination and use of research findings and ultimately in the reduction of health disparities. Community-based research (CBR) is rapidly gaining recognitions as an important tool in addressing complex environmental, health, and social problems (Israel, Schulz, Parker, & Becker, 1998; Lustig, Weems, & Strauser, 2004). "Outside expert"-driven research approaches have been proven ineffective, and communities across North America are demanding that they be given greater decision-making power over studies that take place in their midst. Therefore, CBR is not a method, but an approach to research (Wallerstein & Duran, 2003), that emphasizes the importance of collaboration, participation, and social justice agendas over positivist notions of objectivity and the idea that science is apolitical (Minkler, Blackwell, Thompson, & Tamir, 2003).

In the KARRN projects, the approach was adapted from the participatory rural appraisal (PRA) strategy as described by Kuipers et al. (2001). PRA is a research and development approach for shared learning between local people and outsiders. It is based upon the World Health Organization's model of community-based rehabilitation. Using qualitative methods, volunteers and key informants were recruited to participate in the study. In-depth interviews and discussions were conducted, with the long-term goal of creating an ongoing community-based group interested in issues related to rehabilitation in rural Appalachian Kentucky.

The development of KARRN was a natural extension of the community-based project. Through developing partnerships with the "participants," the group had the conduit for keeping them connected and having the group come together. After the completion of data collection, all participants were invited to take part in a 1 day retreat to discuss the findings from the study and to explore a potential formalization of the group.

The creation of KARRN included multiple steps: initial data collection, partnership development, asset mapping, and developing a group consensus of priorities for KARRN. The group was intentional in approaching group development from a positive point of view by conducting an asset mapping session versus a needs assessment. This framed a strength-based approach, in recognizing the benefits, talents, and gifts that were present in the community. This is in contrast to a needs assessment approach, in which gaps, missing elements, and areas of want or need are highlighted. In addition to the community asset mapping, a formalized shared mission for the network was developed. Results from the study and the asset mapping meeting were used to develop short-term and long-term goals for the group.

KARRN has been active since 2005. It includes people living with neurologic disorders, healthcare providers who work with people with neurologic disorders, university researchers, related local nonprofit programs, vendors, and hospital administrators among others. As a group, the KARRN members meet monthly via a telehealth system which provides a mechanism for people to meet face to face in regional groups and use videoconferencing technology to connect all of the sites together with audio and video. The main focus areas of KARRN that were established and agreed upon by its members include:

- Education: for healthcare providers, clients, and caregivers and communities
- Advocacy: for clients and caregivers and community
- Share information: help to match persons with state and community resources

- Research: to improve long-term healthcare and quality of life
- Increase quality of life and community participation: of persons with disabilities in rural Kentucky
- Sustainability: set up so the group does not have to rely solely on grant funding for continued existence

With these areas of focus in mind, KARRN has hosted an annual conference and developed educational video series available through the KARRN website and brochures related to travel tips and to accessibility of state parks, thus enhancing community access.

In terms of research, KARRN has resulted in the establishment of the Kentucky Stroke Surveillance database that is being used to impact research and service provision. Currently, a study is in progress looking at the impact of a community lay health navigator for people in Appalachian Kentucky who have had a stroke. As a community-based organization, any research that takes place with the support of KARRN must in fact provide something tangible to the participants and the community. It is not the intent of this collaborative to partner with people who want to stop by and collect data and subsequently move on. There must be a benefit to the KARRN members in some way to partner with researchers. In essence, the research must be translated into some meaningful form that has practical applications for the research participants.

With regard to advocacy, an offshoot group, the Kentucky Congress on Spinal Cord Injury, has developed out of KARRN. KARRN group members with shared life experience of spinal cord injury sought additional avenues to promote needed social and legislative changes based upon barriers they faced in their communities. The group recognized the powerful voices that could be used to create positive changes for people with SCI and all people with mobility limitations. This further highlights the reach and new directions that can result when capacity is built in rural communities through meaningful collaborations.

The Role of Rehabilitation Professionals

There is an important opportunity for rehabilitation professionals in capacity building in rural rehabilitation. Rehabilitation counselors and administrators recognize their roles within a collaborative environment and work effectively as part of a collaborative effort. The importance of collaboration to the profession is highlighted in the Code of Professional Ethics for Rehabilitation Counselors (Commission on Rehabilitation Counselor Certification [CRCC], 2017, Section E.2.a.):

> Rehabilitation counselors who are members of interdisciplinary teams delivering multifaceted services to clients must keep the focus on how to serve clients best. They participate in and contribute to decisions that affect the well-being of clients by drawing on the perspectives, values, and experiencesof their profession and those of colleagues from other disciplines.

Rehabilitation counselors and administrators can positively impact capacity building opportunities in rural populations through team building. The knowledge base of rehabilitation counselors can be used to help identify beneficial collaborations at the local level. Also, rehabilitation counselors can help collaborators express shared values and vision. Rehabilitation administrators can assist in initial communications across agencies to help identify commonalities across missions, even when it may not be immediately apparent. The following case study provides an example of how this can work.

Case Study

One area of need for a consumer in a rural area of the state was around mobility. The driveway ended approximately 100 feet from the entrance of her home. To get to the front door, there was a substantial incline, with a narrow dirt path filled with various obstructions (exposed tree roots, protruding rocks, etc.). The consumer was a manual wheelchair user and could not independently get from her vehicle to the house or enjoy any of the areas outside the house. When putting together a team for this case, her vocational rehabilitation counselor immediately thought about the rehabilitation assistive technologists (who were overwhelmed with referrals) and about the expertise at a local university. She spoke with her supervisor, who contacted the school. Initially, the school staff attempted to connect them with disability support services. However, as the administrator and university employees continued the conversation, she was put in touch with both the engineering and landscape departments. An interested faculty member became involved who subsequently saw this as a student research project. The consumer outcome included improved access to the exterior of the home. The outcomes at a capacity building level included new connections between the state VR agency and the university, as rehabilitation technologists were added as guest lecturers in both engineering and landscape. More students had preprofessional projects to include rehabilitation and community building efforts and, subsequently, gained a better understanding of rural rehabilitation.

Summary

Ultimately, the goals of collaboration in rural settings will result in improved outcomes for people with disabilities. But that is just the beginning. Bringing together the right collaborators to address issues in rural rehabilitation can lead to mentorship, enhancement of natural supports from within the community, and additional resources. Availability of federal funding can also help to foster collaboration across agencies. One example is Partnerships in Employment Systems Change grants, through the US Department of Health and Human Services' Administration for Community Living. These grants, funding states, establish consortia of various state agencies to work toward improving employment opportunities for those with disabilities. While this represents a very formal approach to collaborative efforts, it further highlights the need for collaboration to take place at all levels in order to effect real change.

As demonstrated in the example of the Kentucky AgrAbility case study described in this chapter, the action plan shows the opportunity for a collaborative partnership between Kentucky AgrAbility and disability providers in the state. Based upon the approach of community-based participatory research (CBPR), the Kentucky Appalachian Rural Rehabilitation Network (KARRN) provides a powerful rural example of a collaborative that was intentionally developed to improve the quality of life of individuals with disabilities in Kentucky and ultimately improve the systems around supporting people with disabilities. Additionally, the capacity building of KARRN created an advocacy group called the Kentucky Congress on Spinal Cord Injury. The final case study in the chapter documents the important contributions rehabilitation professionals can make through developing collaborative partnerships and increasing capacity building. In turn, this can lead to better outcomes and improved quality of life for rural residents. As shown in the case studies in this chapter, creative collaborations can build capacity within rural communities and also build capacity for the field of rehabilitation.

Ultimately, rehabilitation professionals can play an important part in building and sustaining meaningful collaborations. Successful collaborations include knowledgeable and engaged partners, willing to share time and expertise around a common goal. Though barriers to collaboration exist, it is ultimately in the best interest of everyone involved to work together to support success in rural communities.

Web Resources

Extension: nifa.usda.gov/extension
KARRN: www.karrn.org
National AgrAbility: www.agrability.org

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Utilizing Indigenous Volunteers and Paraprofessionals for Disability Advocacy and Service in Rural America

37

Benson Kinyanjui and Debra A. Harley

Overview
While acknowledging that much progress has been made for inclusion of people with disabilities in the United States, mainly due to several landmark legislations in the past 50 years, many people with disabilities, particularly those who reside in rural areas, are yet to fully benefit from those developments. Research on the subject of rural vocational rehabilitation suggests a clear agreement that rural people with disabilities do not receive the same level of services as their counterparts in metropolitan areas. Equally well defined are the reasons for that disparity, with lack of transportation in rural areas undisputedly identified as a single most important reason for the inequity (Iezzoni, Killeen, & O'Day, 2006; Putnam & Tang, 2005; Rigles, Ipsen, Arnold, & Seekins, 2011). Other commonly cited reasons are poverty and low educational levels in rural areas (Bennett, Olatosi, & Probst, 2008; Nelson, 2010). At the heart of this is a shortage of rehabilitation counselors in the state VR system; precisely the lack of counselors who are available to work closely with people with disabilities in rural areas. Closely tied to this is a lack of sufficient funding for provision of services to people with disabilities. There is little information, however, on how people with disabilities in rural areas can have equal access to rehabilitation services or how the disparity can otherwise be eliminated.

In the United States, the use of paraprofessionals in the disability field was pioneered in the second half of the twentieth century for the purpose of providing support to students with disabilities (Giangreco, Edelman, Broer, & Doyle, 2001; Griggs, 1973; Omohundro, Schneider, Marr, & Grannemann, 1983; Rojewski, 1992). Historically, the concept of paraprofessional working with people with disabilities was precipitated by a shortage of qualified professionals in the fields of special education several decades ago. Since then, paraprofessionals, also known as paraeducators, have been an indispensable part of special education. However, the concept of utilizing paraprofessionals in VR is not new either. Cook, Ferritor, and Cooper (1981) mention several projects in the 1960s and 1970s that had employed that concept including one that recruited rural housewives to perform some VR duties to ensure continuity of services in the 1960s and another that utilized public health nurses to provide counseling, identify community resources, and make referrals on behalf of VR counselors. Those strategies were necessitated by a shortage of rehabilitation professionals and the constraints of time and funding

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B. Kinyanjui (✉)
Collin College, ACCESS Center for Disability Services, Plano, TX, USA
e-mail: kinyanjuibenson@yahoo.com

D.A. Harley
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: dharl00@email.uky.edu

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for rehabilitation counselors' travel. There is, however, no clear indication in the literature as to why that trend did not continue. In fact, there is almost no research at all conducted on volunteers and paraprofessionals in VR counseling. The only empirical studies available on the subject (Crisler, 1973, 1976; Matheny & Oslin, 1970; Mitra, Fitgerald, Hilliard, & Baker, 1974; Sawatzky & Paterson, 1982) are considerably dated. Notably, those studies (Brown, 1974; Hattie, Sharpley, & Rogers, 1984; Hoffman 1976; Kase, 1972) reported paraprofessionals in rehabilitation counseling as having been highly effective.

There is no clear information available on why the practice, which was apparently effective and widespread in the late 1960s and 1970s, did not continue to the present in rehabilitation counseling as it did in the field of special education. However, judging from the limited available literature from that period (Crisler, Porter, & Megathlin, 1969), several factors may have played a role in its discontinuation. First, some administrators and professionals in counseling perceived paraprofessionals more as competitors than as an integral part of the helping profession. Salomone (1970) noted, “Rehabilitation counselors in general seem to be threatened by the growing utilization of rehabilitation aides in public and private agencies” (p. 4). Also, according to Patterson (1968), rehabilitation counselors did not want to give up coordinating functions, which apparently were automatically relegated to rehabilitation aides. Second, the employment of rehabilitation aides appears to have been tied to the Economic Opportunity Act of 1965 as a job creation measure for poor people. That incentive to employ paraprofessionals appears to have faded with the subsequent economic recovery. Third, the rehabilitation counselor paraprofessional position was subject to career ladder procedures (Salomone, 1970) which meant that with time (training, education, and experience), the paraprofessional became a fully qualified rehabilitation counselor professional. Fourth, as master's level education and credentials became more and more recognized and accepted in the industry as the standard definition of rehabilitation counselors, the use of personnel who were not thus qualified was diminished.

In this chapter we propose to revisit use of paraprofessionals and indigenous volunteers and discuss some alternative options that could potentially be considered to enhance VR services in rural areas. Precisely, the chapter explores the utilization of indigenous volunteers and paraprofessionals as a potential solution to the service disparity, discusses the benefits and challenges of that approach, reviews ethical and legal concerns of using volunteers and paraprofessionals, and concludes by addressing future implications that could potentially affect service delivery. Due to a significant lack of current or recent literature on this subject, we will occasionally assume a somewhat descriptive, subjective stance as we explore what appear to be reasonable options based on the current VR scene and also on personal viewpoints. To assist the reader, we provide definitions of paraprofessionals and indigenous volunteer paraprofessionals to understand these roles in rural communities.

Learning Objectives

By the end of this chapter, the readers should be able to:

1. Define the differences between rehabilitation counselors, paraprofessionals, and volunteers.
2. Identify the advantages of using volunteers and paraprofessional in rehabilitation service delivery to clients in rural communities.
3. Understand the ethical and potential legal concerns of using volunteers and paraprofessionals.
4. Identify the roles for volunteers and paraprofessionals in rehabilitation service delivery.
5. Describe the process of obtaining and retaining nonprofessionals to assist with rehabilitation service delivery to people with disabilities in rural areas.

Introduction

According to the 2010 Census, the urban areas of the United States contain 249,253,271 people, representing 80.7% of the population, and rural areas contain 59,492,276 people, or 19.3% of the population (US Census Bureau, 2012). While urban living is associated with convenience and easy accessibility to many of life's necessities and comforts, many people including people with various types of disabilities choose to live in rural settings for a wide variety of reasons among them, less traffic and congestion, a direct connection with nature, friendlier communities, peaceful atmospheres, and slower-paced living. Similar to their counterparts in urban settings, people with disabilities in rural America want to take part in community life and live independently. More importantly, many of them, especially those who held jobs prior to their disability, aspire to be engaged in gainful employment and to become productive, financially independent citizens. In order to do so, they may need community services, support, and advocacy to help meet their needs. Specifically, they need VR services to assist them in preparing for, obtaining, and maintaining employment consistent with their residual abilities. These services are typically provided by VR counselors that are employed by the state and trained to provide advocacy, support, mentorship, and leadership for people with disabilities. Unfortunately, the shortage of rehabilitation personnel in rural, frontier, and territory (RFT) regions of America is a stark and persistent reality. Often, the end result for people with disabilities in rural areas is long wait times, which frequently result in failure to follow through with services. To counter that potential negative outcome, paraprofessional and indigenous volunteers offer a means to which the delivery of services can be supplemented and enhanced.

Challenges of Rural Areas in Use of Volunteers and Paraprofessionals

In the field of vocational rehabilitation counseling, an increase in the numbers of people with disabilities requiring VR services significantly in the past 20 years has not been met with a corresponding increase in the numbers of rehabilitation personnel to serve those people. Consequently, this has resulted in a critical shortage of rehabilitation counselors (Tansey, Bishop, & Smart, 2004) in most parts of the country as the number of state VR counselors has actually decreased due to many states implementing a hiring freeze of rehabilitation personnel during the recent economic downturn. In fact, many states stopped hiring new VR personnel, in many cases not even to replace those going into retirement. While the shortage of rehabilitation counselors definitely affects all VR clients in that they may not receive quality services from counselors who may have had to take on larger caseloads, it is perceivable that clients in rural areas are most negatively affected. Whereas previously urban-based VR counselors might have had time to travel to a rural location to meet with a client or with potential employers, they may no longer be able to do so due to the shortage in human resources.

To the urban rehabilitation counselor, people with disabilities in rural areas are hard to reach, meaning that they are often difficult to identify, difficult to meet with, difficult to communicate and maintain contact with, and consequently difficult to serve (Eng, Parker, & Harlan, 1997). For people with disabilities who live in frontier territories (e.g., Montana, Alaska) and rural regions (e.g., Appalachian regions of West Virginia and Eastern Kentucky), that means possibly never receiving VR services. Viable alternative options in such cases would be the recruitment of indigenous paraprofessionals to provide VR services, albeit not the full range of services that a professional rehabilitation counselor could provide but adequate basic services to steer the person with a disability toward vocational independence. Paraprofessionals are generally utilized for two primary reasons, namely, to augment a shortage of trained professional staff and to overcome cultural barriers.

Who Are Paraprofessionals and Indigenous Volunteers?

By definition, paraprofessionals are people who work in a profession in which they have not received formal training, performing paid or unpaid duties for a professional organization. In other words, these are people to whom particular aspects of professional tasks are delegated but who are not licensed to practice as fully qualified professionals. Typically, paraprofessionals relate closely to or have an interest in the target group being served by a program and perform duties that place them in direct contact with members of that group (Keune & Gelauff-Hanzon, 2001). An indigenous paraprofessional is one who hails from the same cultural background and geographical location as the client; who shares similar lifestyle, language, and general demographic characteristics with the client; who shares common cultural, social, and community values, attitudes, and behaviors with the client; and who is able to communicate with the client as a peer (Blount, Elifson, & Chamberlain, 2014). Other indigenous qualities include being able to understand a client's verbal and nonverbal language, understanding the client's community beliefs toward health and disability, and knowing the actual barriers to services that the client and others in similar situations face (Giblin, 1989). According to Sawatzky and Paterson (1982), an added advantage to using indigenous paraprofessionals is that they can be selected with a view to the commonality that they share with the population needing help. That is, "people from similar communities, settings, age groups, and problem backgrounds are viewed as having a potentially high level of empathy with each other" (p. 28).

In situations where the professional, in this case the rehabilitation counselor, is different from the client in terms of living experiences (such as urban versus rural life experiences), or is otherwise dissimilar racially, ethnically, culturally, linguistically, or socioeconomically, an indigenous paraprofessional could be utilized to work alongside or on behalf of the professional, acting as a bridge over the counselor-client differences. Conceivably, indigenous paraprofessionals identify with the client and are able to more easily establish rapport with him or her, in many cases making them more effective than the VR counselors working with the client (Blount et al., 2014; Durlak, 1979; Matrone & Leahy, 2005). This may also be due to the higher interest and enthusiasm associated with paraprofessionals and their ability to demonstrate empathy, warmth, and genuineness (Durlak) than professionals.

In many parts of the developed world, volunteers (lay people) and nonprofessionals indigenous to those areas (local communities) play an important, central role in the rehabilitation of people with disabilities. In those countries, local community members are recruited and trained to provide services to people with disabilities who live in those communities. The model typically "utilizes volunteer and paid field workers who are indigenous to the area, speak the local language and dialect, know the local customs and social mores, and are already acquainted with the local resources and services" (Zambone & Suarez, 2010, p. 30). These aspects of rural life incorporate self-reliance and a strong commitment to family and church (Kane & Ennis, 1996) and present a system on which the people with disabilities can rely.

In developing countries the utilization of informal caregivers in the provision of services to people with disabilities is not a new concept but rather one that has coexisted with formal services for many years. Be they members of the family, members of faith communities, nongovernmental agency workers, social workers, or community-based rehabilitation workers, these people provide formal and informal services that are typically provided by professional rehabilitation counselors in developed countries. Generally, services include basic support with activities of daily living, mentorship, advocacy in disability matters, leadership, coordination of treatment, referral to available services, education and training pertaining to the specific disability, transportation, counseling, adaptation and innovation of assistive devices, vocational training, job placement, job coaching, and other services as dictated by the nature of disability, the environment, and available resources.

At the core of the system is the immediate family of the person with the disability. In most cases the family provides 24-h residential support and case management (Kane & Ennis, 1996) as they interact on a constant basis with the individual with a disability. The family is the most important natural system and resource in the rehabilitation process of the person with a disability as it is often responsible for the most crucial aspects of rehabilitation. The responsibilities may include monitoring disability or disease symptoms, ensuring compliance with medications and home exercise programs, encouraging adherence to VR plans, and ensuring attendance at scheduled appointments including job interviews.

Informal healthcare providers play a significant role in the world, particularly in developing countries where they are perceived as convenient and affordable and as a means of traversing social and cultural barriers (Sudhinaraset, Ingram, Lofthouse, & Montagu, 2013). Studies on informal care networks have found that parents and spouses of people with disabilities comprise the majority of nonprofessional support for people with disabilities (Elliott & Schewchuk, 1998; Robinson-Whelen, & Rintala, 2003). Outside of the family circle, informal, indigenous care providers come in the form of nonprofessionals and paraprofessionals including spiritual leaders who may voluntarily provide forms of counseling to help the people with disabilities cope with their disability or provide family therapy to members of their families directly impacted by the disability. In rural communities of developed countries including the United States, family members have long assumed the role of paraprofessionals in providing care, coordinating services, and making appointments for those with disabilities and chronic illnesses.

Although rural communities are heterogeneous, they all have some natural strengths based on cultural trends that are common across rural communities in the United States. Among those are a commitment to family, religion, and to faith and social communities (Kane & Ennis, 1996). However, much of the research done pertaining to rural areas has consistently confirmed the challenges of people with disabilities in those areas and commonly highlighted deficits in almost all of the studies. Unfortunately, many studies simply describe the deficits or document the disparities in quality of life or vocational outcomes between urban and rural areas without exploring how the situation could be improved. More importantly, few if any studies focus on the natural strengths of rural areas and their impact on the people with disabilities who live there, in particular how those strengths can compensate for the deficits in formal VR services, including the absence of VR counselors. (See Chap. 7 for discussion on resilience and strengths of rural communities.)

The potential availability of indigenous volunteers and lay people willing to assist individuals with disabilities in various capacities is one of the greatest strengths in rural vocational rehabilitation. Through those indigenous supports, rural lay people can play many different roles in the rehabilitation of individuals with disabilities including companion, transporter, interpreter, or aide, either as the sole support or by supplementing support services provided by the individual's family. Other indigenous supports in the form of lay helpers may include the individual's spiritual leader such as a pastor or rabbi or spiritual healer such as a medicine man or shaman. Nevertheless, even with those supports being available, challenges do exist in rural areas pertaining to the availability of services and service providers.

Based on a review of literature, there is no indication that the field of rehabilitation counseling currently utilizes indigenous volunteers, lay people, or paraprofessionals in the provision of services to people with disabilities in any context. It must be noted that New York's ACCESS-VR program and VR agencies in two or three other states employ VR Counselor Assistants (VRCAs) to assist rehabilitation counselors with some of their duties including administrative and routine communication tasks such as paperwork, record keeping, and scoring assessment tests. Those VRCAs are required to have at least a bachelor's degree or 4 years of qualifying experience. Essentially, those counselor assistants are full-time paid employees who do not provide any VR services directly to clients and are, therefore, significantly different from volunteer paraprofessionals discussed in this chapter.

Rural Challenge that Supports Use of Indigenous Paraprofessionals

Residents of rural areas have and continue to have barriers to education, healthcare, substance abuse treatment, transportation, housing, employment, and other resources. A combination of these factors has rural VR clients at a significant disadvantage compared to their urban counterparts. In addition, people living in rural areas do not have adequate numbers of service providers that could give them access to services in a timely manner. In this section, we discuss challenges in rural communities that support the argument for using community or indigenous volunteers and paraprofessionals.

Lack of Qualified Personnel

The shortage of qualified personnel in rehabilitation counseling and other health and human services professions has existed for decades. Over 50 years ago, Salomone (1970) and Pearl and Reissman (1965) described a serious shortage of rehabilitation counselors, which was predicted to worsen with time. Today, that shortage is a reality and is aggravated by cuts in federal and state funding, which has resulted in a decrease in the number of qualified rehabilitation counselors in state agencies. Unfortunately, the decrease has coincided with an increase in the numbers of people with disabilities due in part to more disabling injuries sustained in Iraqi and Afghanistan wars and higher survival rates among those wounded veterans. In addition, workplace injuries, vehicle accidents, addiction-related behaviors, and environmental hazards have further contributed to that increase.

Caseload Size

Counselors in rural areas often have large caseloads because of having to cover larger geographical areas, requiring them to travel to rural areas in order to meet with clients. Further, large caseloads typically preclude VR counselors from spending much time with their clients (Arnold & Seekins, 1997, 1998; Rigles et al., 2011) or establishing and sustaining rapport, factors that generally contribute to the development of a strong working alliance between counselors and clients (Lustig, Strauser, Rice, & Rucker, 2002) and consequently to positive vocational outcomes. The absence of these factors as dictated by time and distance in the case of rural clients means that counselor caseload sizes may lead to higher client attrition in rural than urban areas.

Types of Disability

Although the lack of services affects all people with disabilities who reside in rural areas, the dearth of resources is especially pronounced for those with mental health-related disabilities. As several studies have found, people with severe mental illnesses are not only disproportionately represented in poor rural areas but are also significantly underserved in comparison with those in urban areas who typically have more services within their reach (Wagenfeld, Murray, Mohatt, & DeBruyn, 1997; Kane & Ennis, 1996). For people with severe mental illness in rural areas, the lack of adequate services leads to functional deficits that interfere with their ability to perform their activities of daily living, diminish their social functioning, and limit their vocational functioning, thus propagating the cycle of poverty and illness. (See Chap. 26 for information on mental health issues.)

Timeliness of Services

The amount of time it takes for persons with disabilities in rural areas to receive services is a contributing factor to their premature exit from services. According to Lustig, Strauser, and Weems (2004), out of the 50% of VR clients who discontinue services prematurely, a significantly high number of them are clients who reside in rural areas. For example, Johnstone et al. (2003) found that among all clients with TBI diagnosis, 79% of rural clients prematurely discontinued services compared to 52% of urban clients.

Linking

Indigenous paraprofessionals serve as links between the client and the professional or agency in charge of providing rehabilitation services; essentially bridging gaps that may exist between the two entities (Chopra et al., 2004). Whether the gap is cultural, linguistic, or geographical in nature, the paraprofessional as an indigenous member of the population in need of the services connects the two sides ensuring a mutual understanding of each other and of the common goal. It helps, therefore, that the paraprofessional is able to communicate freely with the client and for him or her to be perceived by the client as having mutual interests. That being said, an effective paraprofessional functions not only as a member of the recipient community or group but also as a member of the provider agency, in this case the state VR system. Clarity and transparency in these dual roles (identification with and responsibility in both community and agency) are crucial to the success of the paraprofessional. If a paraprofessional loses identity or acceptance in either side, his or her utility as a bridge between the two sides is significantly compromised.

In cases where the client is significantly different from the VR counselor's in culture and language, as is often typical with non-English-speaking Hispanic or immigrant and refugee clients, the indigenous paraprofessional is particularly vital. Besides, using paraprofessionals to reach cultural or linguistic minorities in urban, suburban, or rural settings not only increases provision of services to those people but also helps make the rehabilitation institution more multicultural (Keune & Gelauff-Hanzon, 2001) as it expands and diversifies its reach among individuals from ethnic minority cultures. Studies on refugees and immigrants with disability have consistently found that language is the single most significant barrier to their accessing health and rehabilitation services.

Service Provision

Arguably, the primary role of the paraprofessional is providing VR services to the individual with a disability. Acting on behalf of the VR counselor, the paraprofessional meets with the client or otherwise maintains communication on a regular basis; staying abreast of all developments in the client's rehabilitation. In that function, the paraprofessional ensures that the client receives, in a timely manner, services that would otherwise not be provided to him or her due to unavailability of the rehabilitation counselor. Those services may include some forms of vocational assessment that do not necessarily require administration by a trained professional. These include vocational work sample batteries and simple academic aptitudes tests. The paraprofessional could also help facilitate or provide guidance on self-administered vocational aptitudes and interest inventories and career guidance tests. However, the question remains as to the qualifications and credentials required of personnel in the provision of VR services. What is your response to that position? (See Discussion Box 37.1)

Discussion Box 37.1

Vocational rehabilitation services are typically provided by qualified rehabilitation counselors who are trained and, in most cases, certified to work with individuals with disabilities. With that in mind, it can be argued that placing VR clients in the hands of volunteers and paraprofessionals is a violation of rehabilitation counseling principles and minimal standards to be VR counselors and should never be allowed. Discuss, presenting your opinion supporting it with information from this chapter and elsewhere.

Currently, job services for most of state clients are provided by job development and placement specialists, many of whom are located in urban areas. These services are therefore largely out of reach for most VR clients in rural and frontier locations as are the services of rehabilitation counselors. Utilization of indigenous volunteers and paraprofessionals in the provision of job development, placement, job coaching, and supported employment activities has the potential for increasing the chances of employment for rural VR clients. Indigenous people in this case have the advantage of knowing the local areas, the places where employment is available or where jobs could be created, as well as self-employment opportunities that the client could realistically engage in.

Advocacy

Another significant function paraprofessionals can assume is that of aide, representative, or advocate, speaking for people with disabilities in matters where they may not know their rights, where their rights have been violated, or where they are not able to speak for themselves. As an integral member of the client's community, well aware of the client's and the community's limitations and also aware of what resources are available within the agency, the paraprofessional is suitably placed to represent the client's interests in public and nongovernmental agencies. He or she is the one to whom the client turns to for help in finding needed services and in sorting out the complex service maze (Reiff & Riessman, 1965; Smith, 1973; Yeh, Hunter, Madan-Bahl, Chiang, & Arora, 2004). As an advocate the paraprofessional can function as a liaison between agencies that provide services from which people with disabilities could benefit, ensuring that the client takes full advantage of any and all available services in support of his or her overall rehabilitation. If similar services are available from multiple agencies, the paraprofessional helps the client in identifying the one that is most suitable for his or her functional ability and that offers the most benefit for him or her.

In instances where services are stated to be unavailable for the client, and where the client would otherwise have settled for that response, the paraprofessional follows up with the agency to find out why the client is ineligible and what needs to be done for him or her to qualify for the particular services. Oftentimes, disqualification from services results from minor policy complexities and bureaucratic red tape that requires time, tact, and patience to navigate or negotiate, which some people with disabilities may not have skills for and for which the VR counselors may not have time. In the advocacy role, the paraprofessional, either individually or collaboratively with the person with a disability, challenges the status quo on behalf of the person with a disability and asks "why" or "why not" questions to personnel at service agencies in response to unavailability of services, physical inaccessibility in the client's environment, etc., thus helping eliminate barriers in the rural client's vocational or other rehabilitation.

Advantages and Benefits of Utilizing Volunteers and Paraprofessionals

A major advantage of using indigenous paraprofessionals is that they are more likely to be accepted by the client and community than urban-based RCs who could be seen as outsiders coming to impose their urban ideas. Moreover, they help eliminate the amounts of time that RCs would spend learning about the community and establishing rapport with its residents (Zambone & Suarez, 2010). Additionally, utilizing paraprofessionals during the introduction and implementation of a program increases the chances for comprehension, participation, and completion by the target group, in this case individuals with disabilities (Keune & Gelauff-Hanzon, 2001).

While the use of paraprofessionals in the field of VR might sound foreign in the United States, the concept has been in existence for many decades globally, where vocational rehabilitation paraprofessionals are actively involved in assisting people with disabilities. This is especially true in developing countries in Africa, Asia, and South America where paraprofessionals help to extend services to geographically remote areas and to underserved populations such as ethnic minorities (Brawley & Schindler, 1989; Mpofu et al., 2007). An enduring shortage of trained rehabilitation professionals in those countries coupled with transportation and communication difficulties significantly limits the provision of rehabilitation services to people with disabilities in nonurban areas which in some developing countries can mean almost the entire country. As a practical step toward decreasing the disparity between services for people with disabilities in urban areas and those in "hard to reach" rural areas, auxiliary personnel with minimal training are routinely utilized to perform some tasks that are normally performed by vocational rehabilitation professionals. For example, in some sub-Saharan countries where rehabilitation counselors are universally unavailable, rehabilitation services for people with disabilities are provided by community health workers with no formal training in rehabilitation counseling (Mpofu et al., 2007).

Although, admittedly sub-Saharan Africa bears little resemblance to rural America, the lack of qualified personnel in both areas has the same negative effect on people with disabilities. It is therefore worth the while to look at approaches that have worked there and in other parts of the world and consider if they could be applied in rural or frontier areas of the United States. A viable approach would be recruiting indigenous people such as retirees from teaching or other human service occupations and providing them with brief training on basic (technical) skills. Ideally, the indigenous nonprofessional would operate at the local community level, working with people with disabilities within a rural area proximal to his or her residence, serving as a liaison between them and state VR professionals and related service providers, and as an advocate for the client.

Paraprofessional Skills

Because paraprofessionals do not undergo full education or training as rehabilitation counselors, degrees or certificates do not apply as criteria for their selection. Instead, an individual's interest and motivation, as well as his or her personality, are the primary considerations. However, some experience in working with people in a human service-related field such as education, social work, faith ministry, healthcare, or law enforcement is an important asset. Presumably, volunteer paraprofessionals with work experience in those areas already have the basic interpersonal skills necessary in being a successful paraprofessional in the rehabilitation field. Skills such as friendliness, sociability, counseling and relationship-building skills, ability to provide support and set appropriate boundaries, confidentiality skills, communication skills, and service coordination skills should be among the primary minimum skills expected of paraprofessionals (Eng, Parker, & Harlan,1997; Kilpatrick, Stirling, & Orpin, 2010).

The paraprofessional's level of education should be high enough for him or her to be able to read and comprehend information pertaining to disabilities and rehabilitation processes. At the very least, the paraprofessional's education should be comparable to or higher than the level of the target population group (Keune & Gelauff-Hanzon, 2001). Irrespective of the geographical setting, in cases where the target population cannot communicate in English, the ideal paraprofessional is one who is able to speak the official language (English) and the client's native language. In order to be effective, a paraprofessional must be able to demonstrate authoritative posture in interaction with clients and service providers. That authority should be drawn from character, life experience, and status within the target group or community (Keune & Gelauff-Hanzon).

Paraprofessional Training

In order for volunteers to be effective in serving people with disabilities, they would need to be provided with some form of introductory training aimed at familiarizing them with the scope of activities or tasks that they will be performing for people with disabilities. In the absence of that, the services will be fragmented and disorderly as each volunteer proceeds to do what he or she perceives to be best for the client. Also, without training, paraprofessionals are likely to perceive their role as unimportant to the VR agency and probably not take it seriously. More importantly, initial or in-service training essentially creates the opportunity for the paraprofessional to meet with the rehabilitation counselor. Absence of that training and contact might lead to low morale, dissatisfaction with the volunteer experience, and even lead to high turnover (Mackenzie, 2011). An introductory training session at the beginning as well as short in-service sessions will help to clarify the volunteers' roles, essentially informing them of what they can and cannot do in the realm of VR services for people with disabilities.

In countries where paraprofessionals are widely used, volunteers or paid nonprofessionals are provided with basic in-service training at a central location or by a traveling trainer (Maynard, 2007; Mpofu et al., 2007). With proper planning, that model is applicable in the United States with or without modifications. In that setting, a trainer such as a qualified rehabilitation counselor could travel to a rural area and provide a one-day seminar to a number of volunteers at a central rural location. One advantage of taking the training to the community is that it increases buy-in and provides the community with a sense of ownership. Alternatively, the VR agency could pay paraprofessionals to travel to its offices for the initial training. Ideally, volunteer paraprofessionals should be provided with an initial one-day training prior to their starting to work with people with disabilities. Thereafter, in-service training would be provided on a regular basis every two or three months during which volunteers can meet with the trainer and with other volunteers and have an opportunity to share ideas. The in-service sessions could be less frequent than every two or three months, but by no means should they be discontinued. Supplemental training if needed could be provided via Internet where available and/or by postal mail.

The initial one-day training should be designed to prepare the new paraprofessional for working with the individual with a disability and should include important information such as how to maintain confidentiality and privacy of client information, professional ethics, and the paraprofessional's role, responsibilities, and limitations. The paraprofessional's dual function as the client's support, peer, helper, and advocate and also as a part of the VR agency should be clarified during this training session. The goal is for the paraprofessional to understand that although he or she may discuss personal information with the client, he or she is professionally and even legally expected to keep the information confidential; sharing it only on a need-to-know basis with those who need it in order to provide services to the client, such as physicians or therapists.

During the training the paraprofessional could also be briefed on professional ethics especially pertaining to inappropriate dual relationships. Specifically, the paraprofessional should be clearly warned against some serious ethical violations such as being romantically involved with the client or engaging in financial dealings with him or her. Additionally, paraprofessionals will be advised on maintaining good faith in their relationship with the client, refrain from being judgmental, and avoid imposing their personal, moral, or religious values on the client. As part of the initial training, paraprofessionals could be given a handbook containing a basic code of conduct for paraprofessionals, information on the ADA, clear guidelines on their role and responsibility, and all contact information for the agency and any other resources. In addition, information on general and/or a specific disabling condition should be provided as needed by the paraprofessional.

Paraprofessional Duties

Since no formal training is provided, paraprofessionals are likely to underestimate or overestimate the scope of their duties. It is therefore important that the paraprofessional, the client, and the VR counselor share a common understanding of the paraprofessional position's capacity. To that effect, the volunteer paraprofessional's essential job functions should be clearly outlined in a formal written job description, which will help to clear the confusion or ambiguity. Typical duties of the paraprofessional would include initiating and maintaining contact with people with disabilities and the rehabilitation counselor; case finding; assessing client interests, needs, and assets; advising; supporting; and advocating for the client. As a resident of the rural community and being geographically close to the individual with a disability, the paraprofessional is best situated to meet with the client as needed to review the rehabilitation plan, discuss developments and progress made toward the goal, as well as schedule activities and set deadlines for their completion. At other times, the paraprofessional contacts the client by phone or in person to remind of upcoming appointments or to follow up on past appointments to determine the outcome. Where applicable, the paraprofessional may accompany the person with a disability to job interviews or medical appointments. The paraprofessional then forwards the information to the rehabilitation counselor telephonically or in writing. Through conversation with the client, the paraprofessional determines issues that may be impeding the rehabilitation progress including the client's family issues or environmental accessibility problems. The paraprofessional plays the role of advisor and mentor to the client helping him or her resolve the problems and refocusing him or her to the rehabilitation goals.

Occasionally acting as intermediary, the paraprofessional advises changes in the client's rehabilitation plan based on circumstances unique to the rural setting which the rehabilitation counselor may not be familiar with. As an example the paraprofessional may on behalf of the client request special consideration for additional time to complete certain activities contained in the job search plan which may be modeled for the urban setting. Alternatively, the paraprofessional with firsthand information on the job situation in the rural area may discuss self-employment options with the client and request allowance for a nontraditional vocational plan from the rehabilitation counselor including special funding arrangements different from the standard job placement plan funding.

Also, as a resident of the rural area, the paraprofessional is in a good position for identifying people with disabilities who are not aware of VR services and referring them to the VR office. By making his or her role known within social and religious communities, the paraprofessional becomes the contact person for anyone who has a disability or who knows of someone with a disability residing in the most remote areas of rural communities. More than that, the paraprofessional as a case finder proactively seeks information on any people known to have disabilities in the community and arranges to meet with them to determine the nature of their disabilities and potentially refer them for VR services. It is important to note that the paraprofessional will be respectful of the person's privacy. At the minimum, the paraprofessional's primary duties and tasks should include those described in Table 37.1.

Paraprofessionals can play an important intermediary role bringing together people with disabilities in rural and frontier regions because they are able to connect with and be respected by the target groups while maintaining contact with VR counselors. Essentially, paraprofessionals can raise basic awareness of people with disabilities in rural and isolated areas, educating them of their opportunities in society and in the labor market. According to Keune and Gelauff-Hanzon (2001), paraprofessionals have been successful at "break-

Table 37.1 Paraprofessional primary duties

Identify people with disabilities not receiving services and educate them on available services in their communities
Guide people with disabilities on how to apply for state VR services
Communicate and collaborate with the rehabilitation counselor on client's circumstances, unique to his or her rural setting
Conduct basic assessment of clients including basic literacy skills when needed
Apprise rehabilitation counselor of rural area issues that rehabilitation counselor may not be aware of
Periodically check on client to discuss progress and keep motivated toward goals
Contact local employers to discuss potential employment opportunities for a specific client
Enlighten employers on benefits of hiring people with disabilities
Discuss supported employment with employers and with the individual with a disability
Discuss with employers potential job accommodations for people with disabilities
Assist the person with a disability with identifying volunteer or paid work opportunities in the community
Coach people with disabilities on how to present at job interviews
Serve as job coach in supported employment cases
Raise awareness of the needs of people with disabilities to community leaders
Advocate on behalf of the person with a disability on matters pertaining to community services and on accessibility issues

ing the individual's isolation and stimulating them to participate in society" (p. 100). Ideally, paraprofessionals and rehabilitation counselors can collaborate to guide the person with a disability in the rural areas to the world of work.

Challenges Associated with Utilization of Paraprofessionals

In the preceding pages of this chapter, we have presented utilization of indigenous volunteers and paraprofessionals in the service of people with disabilities who reside in remote rural areas of the United States. As presented, this concept could very well be the only viable solution to the dilemma of providing VR services to that underserved population, especially given the current economic situation manifested by ongoing significant reductions in government funding to state VR agencies. Engaging rural retired professionals is indeed a win-win situation for all stakeholders. We would be naïve, however, to assume that no problems could emerge with that mutually beneficial arrangement.

Ethical Challenges

As with any setting involving human relations and interactions, there are many ethical and legal issues pertaining to using volunteers in the VR field. In fact, rural settings present ethical challenges different from those of urban areas (Nelson, 2010) due to the smaller populations in the communities, closeness of the people, higher rate of family relationships in the communities and a culture of helping one another, and therefore wanting to know more about one another. Because of these characteristics, Boisen and Bosch (2005) suggested that dual relationships are inevitable in rural areas. Although rehabilitation counselors, social workers, healthcare providers, and other human service providers are bound by ethical codes of conduct, volunteers are less so. Individual organizations may develop a code of conduct for volunteers, but no such code currently exists for volunteers in rehabilitation counseling. In the rural setting, ethical issues pertaining to counselor/client relationships are more pronounced and pose an even greater challenge to the volunteer paraprofessional who is a part of the community. Those issues comprise two primary areas, namely, those pertaining to injury or harm caused to the client by the volunteer and those related to harm to the volunteer.

Harm to Client

Most volunteers are good, morally upright, and well-intentioned people. Even so, the potential exists for them to inadvertently cause harm or injury to the clients that they volunteer to assist. Volunteers are more likely to harm clients in subtle but equally serious ways such as disclosing their private health information contrary to HIPAA standards, discussing their case in public, withholding information that could potentially help the rehabilitation process, imposing their beliefs or values on the client, maintaining inappropriate dual relationships, or being romantically involved with the client. Ethical violations of that kind are probably more likely to occur with paraprofessionals due to their not being as familiar with ethical guidelines as rehabilitation counselors who typically have had education and training on professional ethics.

Though highly unperceivable, harm could also come in the form of sexual or other forms of harassment, negligence, emotional stress, or, in extreme cases, assault or battery. In such cases the organization (VR agency) could be vicariously liable for the harm based on the premise of negligent hiring or retention which essentially means that the organization knew or should have known that the individual has some tendency to cause harm to others but did not do anything to prevent it (Shanlever, 2014). For that reason, due care will need to be taken in the recruitment and selection of volunteers to ensure that the risk of harm to the client is maximally diminished. An important step is to adequately screen volunteer applicants and to not utilize any individuals whose character or legal history is unclear.

Harm to the Volunteer

Although the volunteer is not expected to perform any physically demanding tasks which potentially carry a higher risk for physical injury, it is possible for injury to occur on the way to a meeting with the client, while at the client's home, or while at a job site for the purpose of meeting with an employer or in providing job coaching service for the client. In anticipation of such events, matters pertaining to liability will need to be clearly addressed at the recruiting stage and documented in introductory and training materials so that the potential volunteer can understand that the VR agency will not be responsible for such injuries, before they sign up. It should also be made very clear what duties the volunteer is expected to carry out and those that he or she is not to perform, hence the need for an unambiguous job description. This will help decrease the chances of the volunteer performing potentially risky activities while working with the individual with a disability.

According to Fair Labor Standards Act (FLSA) Advisor, volunteers, unlike employees, are not covered under workers' compensation or any other insurance provided by the organization. In the same token, a volunteer cannot successfully sue the organization for injury sustained while working for it except in cases involving gross negligence, recklessness, or willful misconduct (Shanlever, 2014) on the part of the organization.

Confidentiality

The paraprofessional is to be aware that even though issues pertaining to the person with a disability are casually discussed in social circles within the community, a counselor-client relationship exists between the paraprofessional and the person with a disability, and therefore he or she cannot participate in any social discussions about the client. This can be difficult to define, especially if the person with a disability freely shares his or her information, personal or otherwise. The volunteer paraprofessional is to clearly understand that the interest or curiosity of members of the community about the client's rehabilitation status, including the interest of well-wishers and those related to the person with a disability, is not a valid reason to breach confidentiality. In the same token, the paraprofessional is to understand that it is unethical to take on a role or responsibility or attempt to implement an intervention for which he or she is not qualified (Nelson, 2008; Rude & Whetstone, 2008). Maintenance of ethical standards is vital to supporting human rights and, by extension, promoting civil rights and diminishing social inequities.

Legal Challenges

In general, community service agencies and their volunteers are not liable for actions performed while participating in the service program unless those actions are seen as willful and wanton misconduct or gross negligence. Likewise, volunteers are generally protected from being sued by clients. According to the Volunteer Protection Act (VPA) of 1997 (Runquist & Zybach, 2001), a volunteer cannot be liable for actions that occur within the scope of his or her authority as a volunteer for the organization. The Act prevents an individual who files a lawsuit from recovering any punitive damages from a volunteer.

When considering implementing a paraprofessional or indigenous volunteer program, an agency should develop a volunteer agreement and code of conduct. Such a policy should contain certain components (see Table 37.2). This agreement and code are designed to protect all involved parties. In addition, the agency should be prepared to address legal concerns and potential liability that may arise in the use of paraprofessionals and indigenous volunteers.

Certain precautionary measures should be taken in the use of paraprofessionals and volunteers. While acknowledging that it is not possible to guarantee that no ethical or legal problems will ever occur with volunteers and paraprofessionals providing services to rural people with disabilities, several steps can be taken to ensure that the chances of such occurring are significantly decreased. The most important preventative steps occur before the individual begins volunteering

Table 37.2 Components of volunteer agreement and code of conduct

Purpose of volunteer policies
Definition of volunteer
Mandatory service
Volunteers under age 18
Service at the discretion of the agency
Representing the agency
Confidentiality
Screening/reference/background checks
Copyright/ownership issues
Contacting other volunteers
Inappropriate communications
Online safety
Antivirus software
Ending your volunteer role
Dismissal as a volunteer

Adapted from Lynch & McCurley (2006, reprint) and Graff (1996)

for the organization. First and foremost, the requirements of the volunteer position should be listed in recruitment brochures or other enrollment materials so potential volunteers can be aware of them before they decide to volunteer. Information on prohibited interactions or relationships with clients could also be included in those materials to discourage those who may have inappropriate motivations for volunteering. Additional screening of potential volunteers can be completed via formal in-person interviews during which additional questions can be asked and the positions more fully discussed. Once accepted into the organization, the volunteer should be provided with written standards of conduct. Preferably, those rules and standards should be compiled into a volunteer's handbook.

According to Shanlever (2014), an effective way to prevent legal problems is to have all potential volunteers complete a formal written application form for the volunteer position, similar to those for formal paid positions. The application should contain a clause warning against providing false information and the consequences and require a listing of all previous education and employment; a declaration of any arrests, misdemeanors, or felony charges; previous addresses; social security and driver's license numbers; and a list of character references.

Paraprofessional Attrition

An additional challenge of utilizing paraprofessionals pertains to attrition. As nonpaid workers and therefore without an employment contract binding them to the job, volunteer paraprofessionals can stop volunteering at any time they choose, leaving the person with a disability without support. This can create uncertainty in the rehabilitation plan of the person with a disability. Studies on paraprofessional turnover and retention (Farmer & Fedor, 1999; Ghere & York-Barr, 2007; Giangreco et al., 2001) indicate that lack of support is the primary reason for paraprofessional turnover. Lack of or inadequate orientation and training is another commonly cited cause for paraprofessional withdrawal from their positions. Besides providing valuable information and skills, formal orientation leads to a higher level of morale among paraprofessionals as they perceive themselves as being respected and valued (Giangreco et al.). Paraprofessionals who see themselves as playing an indispensable role in the rehabilitation process and as making a difference in the life of the individual with a disability are more likely to continue volunteering than those who perceive themselves as unimportant or somewhat disconnected from the formal rehabilitation system. Furthermore, the dedication or impact of a person with a disability serving as a paraprofessional should be considered (see Case Study).

Case Study

Robert is a 34-year-old Caucasian who lived in an urban area where he worked as an accountant for a fast-growing corporate accounting firm. He joined the company after graduating with an MBA in 2005. In the summer of 2009, 1 month before his wedding, he was walking to his car at a local casino when he was attacked by three men, resulting in intracranial bleeding that left him with a permanent brain injury and loss of vision in his left eye. After months of cognitive rehabilitation, he tried to return to work, but he was clearly unable to perform his duties, and he was terminated from the job with severance pay. In the meantime, his fiancé was no longer interested in marrying him and had moved on.

No longer able to drive and without a job, Robert applied for SSDI and welfare benefits, which he was granted. He continued living in the city while working with the state VR office with the hope of finding a job consistent with his disability. In early 2014, his parents who live on a farm visited him, and when they realized that he was unable to cook or clean and that he was spending all of his money on fast food, taxis, and cleaning services, they advised him to move back in with them on the farm where they could assist him with activities that he was no longer able to perform. Robert would like to return to some form of employment. He contacted the VR office covering his home area and inquired about becoming a paraprofessional working with others with disabilities.

Questions

1. What are the considerations of hiring Robert as a paraprofessional?
2. Do you see any ethical issues?
3. How would you conduct the interview with Robert?

Limitations and Implications for Future Service Delivery

As previously mentioned, there is no indication that the field of rehabilitation counseling currently utilizes volunteers or paraprofessionals or has done so in the recent past. Likewise, there is no recent research on this concept and therefore no current evidence on the effectiveness of paraprofessionals in this particular field. The only empirical studies available on the subject (Crisler, 1973, 1976; Mitra et al., 1974; Sawatzky & Paterson, 1982) are considerably dated, and notably, those studies reported paid paraprofessionals in rehabilitation counseling as having been highly effective (Brown, 1974; Hattie et al., 1984; Hoffman, 1976; Kase, 1972; Mitchell, 1971). Yet, there are no perceivable reasons why the same model could not be successfully implemented and yield a similar level of success in response to the unmet rehabilitation needs of rural people with disabilities. However, care would need to be taken to see that modifications are made to the typical VR protocols to accommodate circumstances that are unique to the rural setting.

Even as the idea presents as a potential solution to the current lack of services for many rural-based people with disabilities, it is not without limitations. For one, there is no certainty that qualified volunteers and lay people can be available in every rural setting who could be recruited and trained to serve as paraprofessionals in the rehabilitation counseling field. More importantly, establishing a volunteer program as suggested in this chapter requires funding which may not be readily available given the fiscal constraints that have led to the decrease in services to people with disabilities. As it is, many states have resorted to an order of selection based on severity of disability in order to conserve funds. It is perceivable that those states may not be amenable to the idea of funding a volunteer recruitment program.

Another limitation pertains to the availability of personnel who would design and organize the program including the development of recruitment and training materials since rehabilitation counselors may not be able to perform those functions because of the large numbers of cases that they typically have to manage. Though the program may prove to be beneficial in the long run, the initial cost of setting up a volunteer program could be prohibitive in terms of materials and staff. Further, the training of volunteers, albeit brief, could present additional responsibilities to rehabilitation counselors already overwhelmed by large caseloads.

We can hypothesize that given the current general sentiments of master's level rehabilitation counselors regarding the utilization of bachelor's level rehabilitation counselors to serve in the same capacity, as dictated by the Comprehensive System of Personnel Development (CSPD) currently being implemented in some states, the introduction of volunteers will most likely not be well received among masters or even among bachelor's level rehabilitation counselors. In addition, rehabilitation counselors might challenge the qualifications and competencies of paraprofessionals and indigenous volunteers to perform these tasks. Such attitudes on the part of trained professionals could negatively affect the training of volunteers, which is essentially provided by trained rehabilitation counselors, and the quality of communication and cooperation with paraprofessionals, which could eventually decrease the amount and quality of services provided to the rural clients with disabilities. The ideal scenario would be for state VR agencies wishing to implement this model to establish a department within its system that is manned by a few volunteer trainers. Understandably, that may not be easy as it may require legislation at the state level.

Summary

This chapter has presented the notion that utilization of indigenous lay people as paraprofessionals to provide services for people with disabilities could potentially reduce, at least in part, some of the current problems with the provision of rehabilitation services for people with disabilities in RFT areas of the United States. This approach has been successfully applied in many parts of the world in developed and underdeveloped countries to provide services to geographically distant and culturally different consumers of health and human services who would otherwise be marginalized and underserved. Perceivably, the model could effectively serve the same purpose in the United States where a significant percentage of people with disabilities reside in rural areas. The approach holds promise for leveling access to VR services in this country, which currently advantages urban-dwelling people who have disabilities. In addition, the approach circumvents the need for substantial additional funding to provide services to this underserved population. In order for the approach to be effective, concerted effort would need to be made within state VR offices to set up a system of recruiting volunteers from rural areas where people with disabilities reside, selecting those who meet set criteria and providing them with basic training in serving people with disabilities.

Resources

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Learning Exercises
Self-Check Questions

1. What are advantages of using paraprofessionals and indigenous volunteers in rural, frontier, and territory communities to provide rehabilitation counseling services to people with disabilities?
2. How early were paraprofessionals used in the United States? In which discipline?
3. How have paraprofessionals been used in various parts of the world?

Experiential Exercises

1. Interview a rehabilitation counselor, regional supervisor, or executive director to assess their attitudes and perceptions about using paraprofessional and indigenous volunteers in rural areas to assist in provision of services to people with disabilities.

2. Develop a plan to recruit paraprofessional and indigenous volunteers in a rural, frontier, or territory area.
3. Develop a code of conduct for paraprofessionals and indigenous volunteers.

Multiple-Choice Questions

1. What is the primary reason for utilizing volunteers and paraprofessionals in vocation rehabilitation services in rural area?
   (a) To save money
   (b) To serve underserved people with disabilities
   (c) To obtain interpreter services
   (d) To provide transportation to clients
2. Which of the following will proper orientation and training allow volunteers and paraprofessionals to perform?
   (a) All VR counselor case management duties
   (b) To understand what VR counselors do
   (c) To handle all cases with caution
   (d) To reduce the chances of ethical mistakes
3. Which of the following is the most important step in the process of enlisting volunteers and paraprofessionals?
   (a) Screening
   (b) Introduction to client
   (c) Orientation
   (d) Meeting the supervisor
4. Which of the following is an advantage of utilizing volunteers and paraprofessionals?
   (a) Know more about the client's disability
   (b) More likely to be accepted by the client
   (c) More likely to be related to the client
   (d) Can easily travel between the counselor and client
5. Which of the following is the most important reason for considering utilizing nonprofessional volunteers and paraprofessionals?
   (a) Eventually will replace the VR counselor
   (b) Bridge the gap between VR counselor and the client
   (c) Ensure the client is kept busy with vocational activities
   (d) All of the above
6. Which of the following became a disincentive to employ paraprofessionals in rehabilitation counseling?
   (a) Economic recovery
   (b) RCs felt threatened
   (c) Career ladder procedures
   (d) All of the above
   (e) None of the above
7. Which of the following is the definition of paraprofessionals?
   (a) People who work in a profession in which they have received formal training
   (b) People who perform emergency duties for a professional organization
   (c) People who work in a profession in which they have not received training
   (d) People who work in a profession in which they have not been tested
8. The existence of paraprofessionals and indigenous volunteers is considered which of the following of rural communities?
   (a) A weakness
   (b) A challenge
   (c) A strength
   (d) A deficit
9. According to the Fair Labor Standards Act, which of the following pertains to volunteers?
   (a) Are not covered by worker's compensation
   (b) Are covered by worker's compensation
   (c) Are not covered by a code of ethics
   (d) Are covered by insurance provided by the organization
10. Which of the following is recommended to prevent legal problems when hiring a volunteer?
   (a) Always Skype the applicant
   (b) Have a written application
   (c) Inquire of local residents
   (d) Keep a copy of driver's license on file

Key

1. B
2. D
3. A
4. B
5. B
6. D

7. C
8. C
9. A
10. B

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Research and Evidence-Based Practices of Vocational Rehabilitation in Rural, Frontier, and Territory Communities

38

Allison R. Fleming*, Bradley W. McDaniels*,
Malachy L. Bishop, and Debra A. Harley

Overview
In this chapter, we consider evidence-based practice (EBP) in the specific context of rural communities. Evidence-based practices (EBP) emerge from a process of evaluation that ensures the selection of the best approach to service delivery based on the current evidence or knowledge available. In EBP, context is important. The often quoted question posed by Paul (1967) identifies the crux of this issue: "What treatment, by whom, is the most effective for this individual with that specific problem, and under which set of circumstances" (p. 111, as cited in Leahy & Arikiosamy, 2010). In the present chapter, the "under which circumstances" part of that question is critical to the consideration of EBP in rural communities because the circumstances are not necessarily the same for a client in a large city as for a client living in a rural area, frontier state, or territory. While practitioners in all areas and regions are encouraged and even mandated to use and apply EBP to their services, there is a real question as to whether EPBs developed in urban and suburban areas are relevant to clients who live in rural, frontier, and territory communities. This important awareness that services or approaches to rehabilitation that are effective for a client in an urban or suburban environment may not be effective for a client living in a rural area, frontier state, or territory has not yet received sufficient consideration. In this chapter, we will provide an overview of EBP, a brief history of how rehabilitation counseling has responded to the EBP mandate, and the relevance for practitioners. Next, we will review identified promising or EBP in rural contexts, and, finally, we propose how research and policy can serve to enhance the application of EBP in rural settings.

Learning Objectives
At the completion of this chapter, the reader should be able to:

1. Describe what is meant by the term, "evidence-based practice."
2. Explain the importance of evidence-based practice.

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*Allison R. Fleming and Bradley W. McDaniels are co-first authors.

A.R. Fleming (✉)
Pennsylvania State University, Rehabilitation and Human Services, University Park, PA, USA
e-mail: apf508@psu.edu

B.W. McDaniels • M.L. Bishop • D.A. Harley
Department of Early Childhood, Special Education, and Rehabilitation Counseling, University of Kentucky, Lexington, KY, USA
e-mail: bradley.mcdaniels@uky.edu; mbishop@uky.edu; dharl00@email.uky.edu

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3. Identify some emerging practices in vocational rehabilitation.
4. Understand how rural context affects the implementation of EBP.
5. Explain how future research can be planned and executed to better respond to the needs of rural clients and practitioners.

Introduction

Rehabilitation counselors and related professionals have a central role in providing services that promote increased employment opportunities, self-sufficiency, well-being, and community inclusion to individuals with disabilities (Fitzgerald, Leahy, Kang, Chan, & Bezyak, 2016). In this role, rehabilitation counselors have an ethical imperative to provide the best possible care and treatment. Evidence-based practice is central to identifying and selecting the best treatment for a specific person in a given situation. The EBP movement has fundamentally altered the way healthcare services are provided (Chronister, Chan, Cardoso, Lynch, & Rosenthal, 2008). The term "evidence-based medicine" appeared in the US medical literature in the early 1990s and, since then, has permeated psychology, allied health, and counseling disciplines (Chan et al., 2010). Rehabilitation counseling has been criticized for being slow to embrace and pursue the identification of evidence-based practices. However, the research-based supporting rehabilitation counseling is broad and growing, and empirically supported practices are increasingly recognized and used in VR agencies (Leahy et al., 2014).

Rehabilitation counselors in rural, frontier, and territory communities share the same ethical imperatives as all rehabilitation counselors to provide services that are likely to be effective and non-harmful to the consumer, while providing sufficient information so that the individual may exercise informed choice in service planning and delivery (Coduti & Luse, 2015). Rehabilitation counselors have reported barriers to identifying and implementing EBPs, such as insufficient time or knowledge to be able to review relevant research, lack of support and encouragement by supervisors and managers, and difficulty locating literature that is easily generalized to the setting or the consumer in question (Bezyak, Kubota, & Rosenthal, 2010; Fitzgerald et al., 2016). Counselors in rural settings face these barriers, but perhaps to an even greater extent due to the relative lack of research focused on the specific issues of consumers in rural communities. Additionally, rural counselors typically must work more independently, with fewer resources and less access to collaborating professionals. Travel requirements may also be different for rural counselors, with some having to travel great distances to see clients who are very spread out geographically. This additional responsibility puts more pressure on counselors and takes time away that otherwise could be spent accessing literature or attending trainings on EBP.

Despite these challenges, counselors and practitioners serving rural, frontier, and territory communities must be aware of and integrate EBP into their practice. In order to do so, they must have an understanding of what EBP is, where it came from, and why it has had such an impact on how we approach rehabilitation and related services.

Defining Evidence-Based Practice

Evidence-based practice is a process used in clinical decision-making by qualified professionals (Chan et al., 2010). It involves an interaction between the clinician's judgment and experience, the best research evidence available, and the client's values and preferences (Sackett, Strauss, Richardson, Rosenberg, & Haynes, 2000). The process is meant to ensure that clinicians make judicious decisions regarding care and treatment of clients through the identification of the clinical question, determination of the best practice or treatment, and then gathering and evaluating the evidence to support the utility of that approach in the given situation.

A hierarchy of evidence has been proposed to allow for uniform or shared standards by which to evaluate research evidence. The hierarchy ranks studies based on the strength of the research methods and trustworthiness of the results. Sample characteristics, research design, methodology, and internal and external validity are considered (University of Canberra, 2016). Winona State University has published a web-based toolkit to demonstrate the hierarchy, levels of evidence, and definitions: http://libguides.winona.edu/c.php?g=11614&p=61584. Evidence that meets the criteria for the higher levels of the hierarchy is considered more trustworthy than evidence that meets the criteria for lower positions on the hierarchy. At the top of the hierarchy are systematic reviews, followed by evidence syntheses, and then critically appraised article synopses. These types of evidence are considered "filtered information" and have already been appraised for quality by nature of inclusion into the synthesis or critically appraised synopsis. This information is appropriate for use in clinical decision-making and may provide greater guidance than other types of reports (University of Canberra, 2016). In the next level of the hierarchy are randomized controlled trials (RCTs), followed by cohort studies, and then other single study results. Information at this level is considered "unfiltered," because the studies have not yet been analyzed in the aggregate or summarized into usable information. The question of whether the results are typical of the treatment and in the population in question has not yet been answered through aggregating these results with other similar studies on the same topic. The user will need to read, interpret, and evaluate the quality and appropriateness for application him or herself. Below these types of studies are background information or expert opinion, which is helpful for clinical decision-making but not as valuable. As qualified professionals then apply the practice or treatment and evaluate the effectiveness of care, this information is used in a continual loop of evaluation and improvement (Chan et al., 2010). An example of how this might happen is found in the Case Study box.

Case Study

Marcus is a licensed professional counselor working for a mental health and rehabilitation agency. He meets his newest client, Janine, who is referred to him for help getting a job. Janine is a 35-year-old single woman and she has a poor work history. She has a high school diploma, but soon after graduation, she began experiencing significant mental health symptoms and was diagnosed with bipolar disorder. She has held jobs on and off in her 20s and 30s, but has not been able to keep a job for more than 2 months. She receives social security benefits and uses them as her primary source of support. Janine states that she would really like to get a job and would like to work in a restaurant. She loves cooking for herself, and even though she doesn't really want to become a chef, she likes being around food and helping others find dishes that they will enjoy. Janine lives in Clearfield County, Pennsylvania and has her own car. She is willing to drive 30–45 min for work.

Marcus gathers as much information about Janine, her current situation, and her work history as he can. He uses what he knows to formulate his clinical question: *What is the best approach to helping Janine get a job, considering that she has not had a strong work history, experiences moderate mental health symptoms, receives social security benefits, and her educational qualifications are limited to her high school diploma?*

Marcus determines that, based on the results of several studies comparing methods, supported employment is the best practice to help Janine be successful. He has found studies comparing supported employment to more traditional vocational rehabilitation methods, as well as reviews of multiple studies evaluating the effectiveness of supported employment for consumers with mental health diagnoses and poor work history. He is qualified to provide supported employment services, as his agency uses this model extensively, and so he works with Janine to find a job and then provides on-site support to her while she learns. He works in an advisory capacity with her employer so that she and her supervisor become used to working together, and Marcus helps Janine manage the stress of starting a new job, meeting new people, and continuing to participate in treatment and personal wellness around her work schedule. He also invites Janine to meet with a benefits counselor so that she can understand how her earnings will impact her benefits, if at all.

Marcus evaluates the effectiveness of the supported employment model with Janine and finds that it has been successful. Janine has a job in a small, family-owned restaurant; she works 2 days a week and assists with several tasks. Her employers are pleased with her performance so far, and Janine is happy with the hours she is working and feels like she is doing well. Marcus will continue to check in with Janine for as long as she needs it and may come back to provide more support if it becomes necessary.

Marcus and Janine made that look easy, didn't they? This example was more straightforward than what many counselors encounter in practice, but it does provide a demonstration of how a professional would go about engaging in EBP. Let's look at how Marcus approached his work with Janine and highlight how he used evidence-based practices to help him decide what to do. First, Marcus met with Janine and learned about her and her goals. Janine was out of work or working off and on for an extended period of time. She continues to experience mental health symptoms of bipolar disorder but participates in treatment and personal wellness activities to manage her condition. Janine expressed interest in working in a restaurant environment, because she loves cooking for herself and loves helping other people find new foods to try that they will like. However, she does not want to cook or work in the kitchen. Once Marcus got to know Janine and her goals, he went through the steps of clinical decision-making with the support of EBP. In step 1, Marcus formulated his clinical question: *What is the best approach to helping Janine get a job, considering that she has not had a strong work history, experiences moderate mental health symptoms, and receives social security benefits and her educational qualifications are limited to her high school diploma?* This created a few subquestions for him to search for evidence to answer the question: What is the most effective strategy to obtain employment when a person has a weak work history? Is supported employment effective for people with mental health diagnoses? Are there other ancillary services that can boost the effectiveness of supported employment for people who receive benefits? Marcus took these questions into step 2: seeking the best evidence available to answer the questions. Marcus searched through databases such as Medline and PsychInfo and found many sources of information to review. He found several studies evaluating the effectiveness of supported employment, including a meta-analysis by Campbell, Bond, and Drake (2011) evaluating the effect of the Individual Placement and Support (IPS) model compared with traditional vocational services for persons with severe mental illness. He was very interested in this work for a couple of reasons: (a) the population in the meta-analysis was relevant to his current work with Janine and (b) a meta-analysis is considered among the more convincing types of evidence to be considered. He took this information combined with the other sources of evidence that he gathered and discussed it with Janine. Marcus is trained in supported employment and is qualified to provide these services, so once he and Janine agreed that it was the best course of action he worked with her to find a work site, and then arranged with the employer to be able to provide on-site support as long as Janine needed it. He and Janine also evaluated the effectiveness of the approach and given her positive outcome, felt it was a good choice.

In other situations, the clinical question may be related to something where there is less available evidence. In this case, a practitioner may have to review other kinds of evidence or seek out expert opinion, as part of the process. In cases where the best available evidence suggests an approach where the practitioner is not qualified, it may become necessary to bring in another professional to collaborate or consult, or seek additional options to ensure that the person implementing the practice is skilled to do so. For rural practitioners, this may present a challenge if there is limited availability of other professionals in the area. In these cases, finding ways to collaborate and/or consult via distance are possible options.

Brief History of EBP and the Rehabilitation Counseling Response

The term "evidence-based medicine" first appeared in the medical literature in the early 1990s (Chan et al., 2010). It was established to promote systematic evaluation of medical research and to ensure that medical interventions were informed by more trustworthy findings than are possible from individual clinical studies (Chronister et al., 2008). Psychology followed (Chronister et al., 2008), and to date, the Clinical Psychology Division of the American Psychological Association (APA) has published a list of 80 treatments that are research supported (APA Presidential Task force, 2006; Society of Clinical Psychology, 2016). By pairing clinical judgments and selection of treatments with research evidence that has greater trustworthiness than single studies, practitioners can have increased confidence in decisions that are made and thus how treatment dollars are spent. There is a financial incentive to use EBP, in so far as it helps to increase service effectiveness and efficient use of resources (Chronister et al., 2008).

Historically, rehabilitation counseling was viewed as having a strong guiding philosophy, but few empirically supported practices to draw from and a research agenda that lacked scientific rigor. Ten years ago, the US Government Accountability office (GAO) suggested that the Vocational Rehabilitation Program was lagging behind scientific advances (US GAO, 2005). As recently as 6 years ago, authors were criticizing rehabilitation counseling for not keeping up with related fields in the development of evidence-based practices (Chan et al., 2010; Tarvydas, Addy, & Fleming, 2010). For a time, it appeared that the discipline of rehabilitation counseling was resisting the EBP movement; criticisms and questions remained about whether or not this approach was consistent with the rehabilitation philosophy and tradition of encouraging the client to make decisions regarding interventions and employing the individualized approach to working with each person (Tarvydas et al., 2010). Others suggested that EBP results in "cookie-cutter health care," where it "undermines the autonomy of clinicians, denying their expertise, insight, and judgment, as well as undercutting the patient's right to make choices between alternative interventions and to prioritize outcomes" (Dijkers, Murphy, & Krellman, 2012, p. S169). Others questioned whether evaluation research where consumers received different interventions (i.e., intervention and control groups) was ethical or even feasible in rehabilitation settings, particularly considering the costs and need for relatively large sample sizes associated with the "gold standard" randomized controlled trials (Johnston et al., 2009). This investment (e.g., cost and number of participants necessary) seems particularly out of balance when findings do not apply to situations or questions that clinicians are facing and thus are not directly applicable to practice (Dijkers et al., 2012). Although these arguments are important to understand and consider, external pressures regarding funding and the viability of the discipline seem to have mandated that EBP be approached rather than avoided in rehabilitation settings.

Vocational rehabilitation in general has been empirically supported (Pruett et al., 2008). Results of literature reviews have detailed factors that relate to positive employment outcomes in rehabilitation settings (Crisp, 2005; Saunders, Leahy, McGlynn, & Estrada-Hernández, 2006).

A few specific services have been evaluated with positive findings, including skills training, supported employment, and counseling and the working alliance (Leahy et al., 2014). While these findings are extremely helpful and represent major progress, the broader question remains: what individual services, for which individual clients in particular situations contribute to the effectiveness of VR? It is good to know that VR is effective, but we do not yet have a clear understanding of which practices are the most, and least, effective.

Outcome research, with meaningful application toward improving services and employment outcomes, is typically the way to address these questions (Fleming, Del Valle, Kim, & Leahy, 2013; Leahy, Thielsen, Millington, Austin, & Fleming, 2009). The Rehabilitation Services Administration and the National Institute of Disability Independent Living and Rehabilitation Research (NIDILRR; formerly NIDRR) have emphasized the need to develop EBPs and provide outcome data supporting the effectiveness of the VR program (Brannon, 2010). Recently, rehabilitation counseling researchers have responded. Fleming et al. (2013) identified 35 studies in which specific VR services or models were empirically supported. These studies were categorized into seven areas: interagency collaboration, counselor education and customer outcomes, services to a targeted group, supported employment, empowerment and customer self-concept, essential elements of service delivery, and miscellaneous vocational services (Fleming et al., 2013). This review served to highlight areas in which evidence for effective practice is accruing but also underscored the limited scope of the existing research, the need for research using more rigorous research designs, and the need for more attention to replication of preliminary studies.

The NIDILRR-funded Rehabilitation Research and Training Center devoted to EBPs in VR (RRTC-EBP) recently completed comprehensive case studies of promising practices in four states (Leahy et al., 2014) and identified four more areas where models of service have been evaluated with promising results: post-secondary transition services, the Individual Placement Support (IPS) model of supported employment, workplace social skills training, benefits counseling, and workplace support services. Others are pursuing randomized control trials of models of services that are directly relevant to VR agencies, and these efforts should be extended (Fraker et al., 2012). An example of this work is the Promoting the Readiness of Minors in Supplemental Security Income (PROMISE) grants, in which the effects of five core service components (formal agency-level partnerships, case management, benefits counseling and financial literacy training, career and work-based learning experiences, and training and information for parents) are being evaluated using experimental design with random assignment (Fraker, Mamun, & Timmins, 2015). The results of these projects will be useful in building the evidence base for rehabilitation services.

Although studies employing randomized controlled trials (RCT) are generally prioritized in terms of contributing to the development of EBP, the use of RCTs in the rehabilitation counseling research has been relatively limited. It is important to recognize, however, that other research designs also contribute to the development of EBP and may be more appropriate and more useful. In RCT, the act of randomly assigning participants to receive or not receive an intervention minimizes and controls for other factors that may lead to significant differences between groups. This makes the RCT a rigorous and convincing design, particularly when results are replicated. However, RCT may not be the best way to answer a clinical question when multiple personal and environmental factors influence the outcome under study (Dijkers, 2009). According to the GAO (2009):

> …the evaluation literature cautions that as social interventions become more complex, representing a diverse set of local applications of a broad policy rather than a common set of activities, randomized experiments may become less informative. … aggregating results over substantial variability in what the intervention entails may end up providing little guidance of what, exactly, works. (pp. 25–26)

In other words, interventions studied under highly controlled conditions may not be generalizable to real-life settings (including rural settings), especially considering the heterogeneity and variation of VR clients and environments (US GAO, 2009). There is a risk of overlooking practices with great potential by solely relying on evidence from randomized experiments.

Alternatives to RCTs might be equally valid depending on the research question, including quasi-experimental comparison group designs, statistical analyses of observational data, and in-depth case studies. For a service system that addresses widely diverse needs among a varied clientele, no one type of approach to evaluating practice will be able to answer all questions equally well.

In summary, a number of conclusions can be made about the current state of EBP in VR. First, it is generally recognized that more research on effective VR practices and services is necessary. Second, a balanced approach to this research will be most effective. While studies using rigorous research designs, including RCTs, will be important to developing EBP and increasing professional and stakeholder confidence in VR, studies using alternate research designs will frequently be more feasible, practical, and more informative. Finally, after a relatively slow start, the rehabilitation counseling profession appears to be committed to increasing the research base, as evidenced in both large-scale and small-scale VR research efforts, and this expanding research base will continue to promote the development of EBP.

How EBP Is Used by Service Providers

The overriding principle guiding the provision of effective service delivery is to offer the best possible services based on the best clinical evidence from the available research (Chan, Tarvydas, Blalock, Strauser, & Atkins, 2009). At its core, rehabilitation counseling research is intended to provide information to both persons with disabilities and practitioners to effectively foster both independence and goal attainment (Bellini & Rumrill, 2009; Chan, Miller, Pruett, Lee, & Chou, 2003). Despite the growing attention to EBP in rehabilitation counseling, however, a sizable gap persists between knowledge developed through research and the service delivery system (Chan, Rosenthal, & Pruett, 2008; Chan et al., 2009; Davis & Sproling, 2012). As noted, this gap is in part due to the inaccessibility of the research for busy practitioners and the limited avenues for dissemination beyond preservice education, professional journals, and professional trainings. Reducing this gap will involve changes for both researchers and practitioners. Knowledge translation is a critical element in this process of change.

Knowledge Translation

Knowledge translation (KT) is a dynamic and iterative process that includes not only the synthesis of knowledge through empirical research but also the ethically sound application of information to improve outcomes (Canadian Institutes of Health Research [CIHR], 2014). One of the overriding objectives of KT is to facilitate the adoption and application of evidence-based practices by practitioners. Following the dissemination of empirical research, practitioners need to have easy access to the findings, have clear explanations regarding how to implement interventions, and share best practices with colleagues (Liu, Anderson, Matthews, Nierenhausen, & Schlegelmilch, 2014). Despite recent research relating effective practices with positive VR outcomes, unemployment rates for people with disabilities continue to be abysmally low compared to people without disabilities (U. S. Department of Labor, 2012). To the extent that this reality reflects the gap between research and practice, the goal of KT is to afford practitioners better access to the research, and thus promote their ability to adopt and implement effective practices and interventions.

Although KT is one way to decrease the gap between evidence-based research and practitioner implementation, other potential barriers remain. For EBP to be successfully implemented by practitioners, the limitations of the end users need to be understood (Anderson, Matthews, Lui, & Nierenhausen, 2014). Some of barriers to the acquisition and eventual application of EBP cited in the literature include insufficient agency resources and/or acceptance of change, limited time, and lack of understanding of research methods (Anderson et al., 2014; Baumbusch, et al., 2008; Graham et al., 2013). VR counselors, on average, have exceedingly high caseloads (Dew, Alan, & Tomlinson, 2008), which often preclude their ability to engage in educational activities or research review. In order to instill in VR counselors the importance of employing EBP, the organizational culture must be one that is willing to accept change and encourage employees to be innovative and remain current on new approaches to improve outcomes (Rijal, 2010; Schultz, 2008). Unfortunately, given the current financial challenges facing many VR organizations, this culture may be aspirational but not fully adopted by the leadership. Finally, Bezyak et al. (2010) reported that many rehabilitation counselors feel ill-equipped with the requisite research knowledge to sufficiently assess research findings and employ EBP analysis, and many are not well versed with utilizing academic search strategies to effectively locate EBP literature.

Needless to say, solutions to these issues are needed and would likely prove beneficial to the ultimate implementation of EBP. However, even as rehabilitation counseling professionals become more familiar with and adept at identifying EBP, it will remain important that professionals pay attention to the population for whom the given intervention was studied (e.g., demographics, disability, contextual factors), which may create challenges when applying interventions or services to populations (e.g., rural consumers) that were not specifically included in, and may not resemble in some important way, the original sample. The Research and Training Center on Disability in Rural Communities (http://rtc.ruralinstitute.umt.edu) specializes in projects and training that are relevant to rural consumers and offers technical assistance, which may be helpful in trying to apply research findings in the rural context.

How EBP Impacts Policy

Accountability for the effectiveness and efficiency of services and outcomes has been mandated by funding organizations since the passage of the Rehabilitation Act of 1973 and continues today within the context of increasing funding constraints (Leahy et al., 2009; Kosciulek, 2010; Rubin & Roessler, 2008). Undoubtedly, all rehabilitation counseling professionals appreciate the fiscal challenges associated with the provision of services in the public sector. There continues to be increased pressure from stakeholders to close more cases at a faster rate in an attempt to continue to demonstrate efficacy and secure state-federal funding. Considering the current concern over resources, government agencies prefer to focus funding toward those services that have demonstrated improved outcomes (Chan et al., 2008, 2010). One example of the paradigm shift toward evidence-based policy decisions can be found in a memorandum issued by the President's Office of Management and Budget (Zients, 2012), which instructs federal agency department heads to consider the following when making resource allocation and grant decisions: "Where the evidence is strong, we should act on it. Where evidence is suggestive, we should consider it. Where evidence is weak, we should build on the knowledge to support better decisions in the future" (p. 1).

According to the National Research Council (2012), the process of effectively applying scientific evidence in policy decisions consists of identifying the problem to be addressed, selecting target groups, assessing the importance of the issue to be addressed, explaining the relevance of the need for change, and evaluating the results after implementation. Evidence is only one variable taken into consideration when policy decisions are being considered, and other factors fall outside the scope of this chapter, but the onus of supplying the research falls squarely on those researchers for whom policy affects. The National Institute on Disability and Rehabilitation Research (NIDRR) and the Rehabilitation Services Administration (RSA) have both addressed the concerns about the development of EBPs by concluding that in a resource-limited market, evidence of the effectiveness of practices can inform programmatic funding decisions in a more rational and equitable way (Brannon, 2010). Furthermore, the Work Incentives Improvement Act of 1999 and the Workforce Investment Act of 1998 both require public vocational rehabilitation organizations to demonstrate effectiveness in order to maintain and increase funding (Koscuilek, 2004). As the Workforce Innovation and Opportunity Act (WIOA) is being implemented, accountability and attention to core performance indicators are increasingly emphasized.

Clearly, policies affect the provision of services provided by rehabilitation counselors and ultimately the outcomes experienced by consumers. Federal agencies that are responsible for policy decisions need to be provided with as much information as possible to allow them to make informed determinations about how to most effectively guide the policy debate. Moreover, this means that in order to be effective, evidence-based research must be presented in practical terms and application in order to adequately inform policy decisions (Rogers & Martin, 2009). Although research indicates that the evidence on the most effective and efficient ways to deliver services remains sparse, an increased focus on EBP can afford policy makers and administrators guidance for improving programs and policies (Kosciulek, 2010). Data may be available demonstrating the overall effectiveness of rehabilitation counselor interventions, but there is a call, indeed, for increased evidence on what specific interventions result in what outcomes for whom. For the viability of the rehabilitation counseling profession, favorable policies and funding resources need to be maintained and improved. EBP is one essential component demonstrating the value of the profession in the lives of those with disabilities. Given the current state of budgetary constraints, government agencies are asking difficult questions about rehabilitation outcomes and demanding objective evidence to justify their ongoing support (Chan et al., 2008).

Rural Services and EBP

Rural, territory, and frontier communities often have a vastly different landscape of services and availability than urban and suburban areas. As is discussed in many other sections of this text, residents face disproportionate poverty and heightened prevalence of disability and chronic health issues, including substance use disorders. Communities are often isolated, requiring that residents fend for themselves and work together to ensure that their needs are met. Many rural communities are losing residents due to difficulty in the local economy and young residents moving away for college or work and not returning home. However, rural communities prove to be incredibly resilient as they respond to crises, reduced public funding because of reduced tax base, and natural disasters. The “take care of our own” philosophy frequently extends to all residents, including those with disabilities. While service organizations face multiple challenges including funding, recruitment and retention of qualified professionals, and serving clients who are geographically spread out with limited transportation, professionals are remarkably adept in filling required roles and are dedicated to meeting the needs of the community. We present this discussion of EBP in rural communities with the acknowledgment that working in a rural community is different than working in urban areas. Counselor training often lacks attention to rural issues, and some new professionals accept jobs in rural areas with limited preparation for the realities. Along the same lines, utilizing EBPs in rural communities will not be the same as it is in urban areas. The following is a review of EBPs within the rural context, with some addition of promising practices in related fields that have been successful in rural communities.

What Works in Rural Areas?

The profession of rehabilitation counseling has limited EBPs from a traditional sense but also has a collection of promising and empirically based interventions. Although the evidence-based service delivery model implemented by most rehabilitation professionals in urban settings is likely applicable to those living in rural communities, as a profession, rehabilitation counselors are charged with utilizing those practices that have demonstrated effectiveness and efficacy for the population being served. In fact, for decades, rehabilitation counseling has been criticized for its urban focus and inapplicability of proffered services in rural settings (Bitter, 1972; Seekins, Ravesloot, & Dingman, 1989). As a profession, rehabilitation counseling has gradually begun to recognize the importance of EBP, not only for improving outcomes based on a theory-driven research agenda but also for the viability and continued growth of the field. Considering this, researchers need to continue to press forward to provide conceptually clear, evidence-based strategies to practitioners, which includes a focus on the inherent challenges of rural service delivery. In the strictest sense, very few, if any, high-quality EBPs exist for rural communities. Therefore, making evidence-based decisions for rural consumers is not likely to be based on research specific to the population but rather based on inferences from broad populations that are either unspecified or likely to be urban or suburban. Two of the major barriers to the use of EBPs are the lack of generalizability of findings and the application of research findings to individual (rural) consumers (Bezyak et al., 2010).

Significant evidence does exist for some of the EBP constructs and interventions routinely used by rehabilitation counselors. These include, for example, establishing a working alliance, skills training, and supported employment. There is little doubt that these strategies and services improve outcomes across different populations, and there is no research-based reason to think that these are not equally effective across settings. Furthermore, when considering the currently accepted EBPs in rehabilitation counseling, evidence clearly supports the effectiveness and efficacy of each modality across a wide range of individuals. That being said, in accordance with rigorous scientific exploration, one should consider whether or not research with a particular group has been thoroughly completed. How do skills training, the working alliance, and supported employment work in rural areas? How does the effectiveness compare with principally urban areas? One could argue, undoubtedly, that these EBPs are effective in all populations, assuming adherence to the established protocols (i.e., fidelity). Although this may be a reasonable assumption, for the rehabilitation counseling profession to be viewed as empirically sound, interventions should and must be based on rigorous and methodologically solid validation and utilization.

Understanding the challenges faced by practitioners providing services to rural consumers and how these challenges affect evidence-based service delivery is the crux of the problem. For example, affording consumer's choice regarding employment options is a critical factor in successful supported employment. Choice, according to Wehman and Kregel (1998), involves "having more than one option from which to make a selection" (p. 9). In many areas of the country, occupational choices may be extensive, but in some rural areas, vocational choices may be extremely limited (Economic Research Service, 2012). Such limitations have potential implications for both the process and outcome of SE services.

The working alliance is an amalgamation of building bonds, establishing goals, and developing tasks (O'Sullivan, 2012). Research has demonstrated that consumers who perceive a positive working alliance with the service provider typically experience more positive outcomes (Donnell, Strauser, & Lustig, 2004; Lustig, Strauser, Rice, & Rucker, 2002; Schronberger, Humle, Zeeman, & Teasdale, 2006). How might the experience of counselors and clients in rural areas affect the development and experience of a positive working alliance? One of the necessary factors for developing a positive working alliance centers on building relational bonds. Due to the inherent geographic and transportation barriers, which can severely limit interpersonal contact, a client and counselor may not have the same level of contact as a dyad in a more urban area. Although limited and dated, there is evidence that the greater the distance between counselor and consumer, the poorer the counselor-consumer relationship (Bitter, 1972; Rojewski, 1992). Alternately, clinicians who live and work in rural communities are often well known by, and may have multiple relationships with residents, which may potentially make the development of a counseling working alliance easier or more difficult.

One of the most glaring challenges to achieving positive outcomes in rural communities is limited or nonexistent public transportation options. Coupled with relatively limited employment opportunities in rural areas, the lack of transportation precludes consumers from considering jobs in neighboring communities. Moreover, consumers in rural areas without public transportation often have difficulty getting to VR and other necessary appointments. (For a full discussion about rural transportation issues, readers are referred to Chap. 33 of this book).

Community Navigators

Community navigator programs are an example of an evidence-based practice model that has been designed specifically for, and found to be very effective with, serving people living in rural or isolated areas. Public health initiatives have capitalized on the value of channeling community members to help each other locate resources and overcome barriers to care. In situations where treatment or care is received away from the community and the professionals providing the care are not familiar with the client's community, ensuring follow-up and continued case management is difficult without a local contact to assist. In a community with few residents, it is not expected that a critical mass of individuals with the same disability issues and needs is easily found. One may return home from intensive acute treatment without knowledge of or familiarity with local resources to help continue management of a disability or health condition. The existence of community navigators who can help a person locate and arrange continued care can mean the difference between being able to manage a condition or disability to maintain optimal function or not doing so and experiencing deterioration and symptom exacerbation as a result. One such example is found in rural Kentucky, through the Kentucky Appalachian Rural Rehabilitation Network (KARRN; Kitzman & Hunter, 2011). This program is further described in Chap. 36. This program is an excellent example of an evidence-based program shown to be effective in rural areas.

Discussion Box 38.1

What are the challenges in developing EBP for counseling in rural areas?

In the chapter, we learned that EBP came out of evidence-based medicine, and that counseling fields have been slower to adapt EBP than other health-related fields. Why is that? There are a few contributing factors. One thing to consider is the different kinds of studies that generate the "evidence" in EBP and how they contribute to the knowledge base. Researchers, when planning studies, are always balancing ensuring the highest level of validity and confidence in the results with practical considerations of being able to carry the project through. Some of the practical issues relate to the sample—such as will we be able to recruit enough participants that meet our criteria? Will people stay enrolled in our study long enough for us to be able to see an effect of a treatment? Will we be able to see that the participants who are enrolled were all given the same treatment, and was it delivered the way we intended? There are two main kinds of validity to consider: (a) internal validity or how well the study is performed with respect to being able to isolate the effects of the treatment as opposed to anything else that might have caused a change and (b) external validity or the extent to which the results of the study can be generalized beyond the specific situation under which the study was performed. A study may be performed under very strict conditions and have high internal validity, but be so specific to the persons and conditions in your sample that you would not be confident that the same results would be found in other people in the community. Conversely, a study may be easily generalizable, but due to variations in settings, characteristics of participants—or other reasons—may have some threats to internal validity that make it hard to be confident that the treatment was responsible for the change and not something else. Both types of validity are critical to developing EBPs for counseling and rehabilitation settings and come with their own challenges.

As we learned earlier, the highest level of evidence comes from not just one study, but from several studies in a meta-analysis or systematic review. However, in order do a meta-analysis or systematic review, there must be a large enough number of studies to review and consider in this kind of summary. The studies must contain enough information about the sample, the treatment, the treatment effects, and be similar enough to be able to compare them. As of now, it is difficult to find sufficient numbers of studies that focus on a specific population, applying the same intervention to be able to do a meta-analysis or systematic review. There are even fewer studies available that focus on residents from rural, frontier, or territory communities. Until we build enough of a literature base to be able to summarize findings across several well-designed studies, practitioners working in rural areas are at a disadvantage in accessing EBPs. However, this does not mean that practitioners are not applying interventions that are successful and effective. The challenge lies in evaluating and recording these successes so that they can be better understood.

Future Directions in EBP for Rural Practitioners

What works in rural areas? From an EBP in VR perspective, at this point, we don't fully know. Due to the lack of attention to rural rehabilitation in the rehabilitation counseling research, there are few empirical answers to this question. One approach that will inform EBP research in rural areas is learning the needs of the end users (i.e., practitioners). Through open dialogue and information gathering, researchers can begin to understand the nature of the problem and begin to search for possible solutions. In the literature, this gap between research and practice has been referred to as a chasm, which needs to be addressed in an attempt to improve innovative service delivery (Murray, 2009). The process of KT offers an important means of bridging the gap. Participatory action research (PAR) has also been discussed as an important approach to reducing the gap between research and practitioners (Anderson et al., 2014). PAR is defined by Green et al. (2003) as "systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change" (p. 419).

One of the beneficial aspects of PAR is that practitioners and consumers are involved in determining what needs to be addressed. This is particularly important to those working in rural areas so that specific barriers and potential solutions can be addressed. This process is predicated on the development of effective working relationships between researchers, practitioners, and consumers (Hergenrather, Geishecker, McGuire-Kuletz, & Rhodes, 2010). Through the establishment of a collaborative approach between rehabilitation researchers and practitioners, the focus of research and subsequent dissemination could be enhanced, resulting in improved outcomes for consumers (Chan et al., 2009). This engagement of practitioners as valued partners in the research process will be critical as rehabilitation counselors move toward adoption of EBP (Anderson et al., 2014).

Another research and evaluation framework that has received significant attention in the health and rehabilitation literature is the RE-AIM model (Glasgow, Vogt, & Boles, 1999). As Strauser and Wong (2010) pointed out, there is a need to not only focus on efficacy-based approaches but also to more broadly assess the impact of interventions on consumers in particular settings. Of particular interest, RE-AIM strives to improve external validity, which is one of the challenges with attempting to generalize results to predominantly rural communities. The RE-AIM model consists of five dimensions: *R*each (e.g., participants from a defined population), *E*fficacy (e.g., both positive and negative outcomes), *A*doption (e.g., representativeness of settings [vocational rehabilitation, center for independent living] that adopt a given intervention), *I*mplementation (e.g., practitioners delivering the intervention as intended), and *M*aintenance (e.g., replicable and long-lasting interventions; Glasgow et al., 1999). RE-AIM allows for researchers to clearly define the reach of their research efforts regarding particular demographic variables, disability type, etc., which makes a valuable addition to the creation of rural EBP. Once the participants have been defined, the intervention implemented, and the efficacy determined, conclusions may be drawn as to the appropriateness of the given intervention for the specific population; thus begins the process of establishing EBP. RE-AIM stresses the importance of involving the target audience (e.g., consumers, practitioners) in intervention design from the beginning to provide meaningful outcomes (Strauser & Wong, 2010).

Although limited research has been focused on rural consumers and their unique challenges, both PAR and RE-AIM are promising models for increasing research, and ultimately EBP, in such communities. Researchers would benefit from working closely with end users in the development of research agendas, as they would be able to provide potential solutions to specific and pertinent issues. Quality research needs to have satisfactory external validity to allow practitioners to be confident that the results are generalizable to his/her particular setting. PAR and RE-AIM are not the only options for improvement, but they undoubtedly have merit and should be considered when attempting to determine what works in rural areas.

Increasing Availability and Use of EBP in Rural Communities

One of the greatest barriers to implementing EBP is the issue of counselor time constraints. Several researchers have reported that having no or little time to find or use research evidence is one of factors that precludes EBP implementation (Anderson et al., 2014; Graham et al., 2013). Besides time constraints, extant literature cites insufficient organizational resources, lack of research availability, and counselors being unskilled with research methods (Baumbusch et al., 2008; Oliver, Innvar, Lorenc, Woodman, & Thomas, 2014). Yet despite the identified barriers, counselors overwhelmingly express an interest in receiving research and training in areas that would result in improved service provision (Anderson et al., 2014). The overriding challenge is to identify effective practices for bridging the gap between research and practice.

Although counselors who work in rural areas do have some unique challenges, the recommendations for how to move forward with EBP in service delivery may be equally effective in both rural and non-rural settings. The organizational environment is a critical factor in whether or not the discovery and sharing of new knowledge is encouraged (Rai, 2011). Fostering an encouraging and facilitative organizational culture that allows practitioners the time and flexibility to engage in KT activities is essential to the overall effectiveness of service delivery. Organizations allowing for increased autonomy and discretion of counselors tend to be more amenable to innovation and informal exchanges of knowledge (Ruppel & Harrington, 2001). Accomplishing such organizational culture change requires a paradigm shift, which is necessary to inform EBP and continue to grow as a profession (Tarvydas et al., 2010). In attempting to bridge the gap, organizations would be well served to afford counselors time on a regular basis to be reserved for research, reading, and attending educational conferences. For change to occur, it is incumbent upon the organization to support the associated activities.

Assuming organizational support, the issue becomes how to address the reported barriers of lack of research availability and the frequently reported lack of counselor research knowledge or capacity in reviewing research articles. Several potential solutions have been proposed in the literature including educational meetings in which experts identify and present key messages in ways that are easily understood and assimilated by different audiences (Forsetlund et al., 2009), educational outreach where a trained person meets providers in their own setting to provide novel information and research findings (e.g., in-services; O'Brien et al., 2007), trainings to teach practitioners how to find and evaluate research through the internet, and rehabilitation counseling journal clubs, which is a group of practitioners who meet on a regular basis to critically evaluate research articles (Kosciulek, 2010; Mobbs, 2004; Russell, Bean, & Barry, 2006). The majority of the aforementioned solutions (e.g., educational meetings, educational outreach, journal clubs) have been well validated empirically.

The overriding factor that must be present for KT to be successful is the collaborative desire to improve knowledge, understanding, and outcomes. Moreover, in order for the gap to be bridged and outcomes to improve, evidence-based knowledge and interventions must be translated practically with corresponding application (Rogers & Martin, 2009). In order for EBP specific to particular populations to be satisfactorily applied, researchers must realize the limitations faced by practitioners and administrators and meet the community where it is, using effective strategies to provide relevant information (Anderson et al., 2014; Hergenrather et al., 2010; Rogers & Martin, 2009).

Research Box 38.1 See Kinoshita et al. (2013)

Determining what constitutes EBP and where to locate appropriate literature is an essential component of quality service delivery. The following is an example of the process of moving from empirical- to evidence-based practice through the use of a meta-analysis. We performed a search of the Cochrane Library seeking meta-analyses of supported employment and have chosen one match for demonstration purposes. This review addresses the employment disparities of individuals with severe mental illness. The authors sought to determine the effectiveness of supported employment (SE) and Individual Placement and Support (IPS; a carefully specified form of SE) versus other approaches to finding employment (e.g., job workshops, job counseling, peer support, partnerships with business). The review consisted of 2259 individuals with severe mental illness drawn from 14 randomized controlled trials. The conclusions confirmed the effectiveness of SE regarding two outcomes: (a) SE increases the length of time for an individual's employment and (b) SE resulted in quicker job placement.

Title: Supported Employment for Adults with Severe Mental Illness

Objective: To review the effectiveness of SE compared to other VR approaches.

Method: Meta-analysis. A search of the Cochrane Schizophrenia Group Trials Register was performed, and randomized controlled trials focusing on people with severe mental illness, of working age, and in whom SE was compared to other approaches were selected for inclusion.

Results: SE significantly increased the levels of employment obtained throughout the course of the studies and resulted in increased length of competitive employment compared to other approaches.

Conclusions: Although not all of the data were considered high-quality evidence, the overall results of the meta-analysis suggest that SE is an effective strategy for improving a number of vocational outcomes for individuals with severe mental illness.

Questions
1. What is the difference between high-quality and low-quality evidence?
2. Why is a meta-analysis considered stronger than individual empirical studies?
3. What is a good resource for finding meta-analyses or systematic reviews?

Summary

In this chapter, we considered evidence-based practice (EBP) in the specific context of rural communities. The field of counseling, and VR in particular, is still in a phase of adopting EPB as a service mandate. EBPs are being developed, but there are questions regarding the extent to which rural communities are being included in these research efforts. Context is critical, and approaches such as PAR and RE-AIM are argued to be useful to ensure sufficient coverage of rural issues in outcome research. Practitioners in rural communities face challenges that are unique from their colleagues working in urban and suburban settings. Having to do more with less and adopt a more generalist approach to services to meet client needs add pressure to the day-to-day for rural counselors. However, the ethical imperatives of identifying the best approach, for this client, in this particular situation are clear. Agencies can implement strategies such as in-service trainings, journal reading clubs, and university partnerships to bring greater awareness of EBP to counselors. Agency culture that welcomes change and innovation and allows for flexibility and counselor control of time and schedule may also support staff in making the effort to be up to date and knowledgeable regarding EPB. Future efforts to include rural samples in outcome research and work directly with rural practitioners to plan and execute studies will be very useful in developing a more universally applicable knowledge base.

Resources

Winona State University web-based EBP toolkit: http://libguides.winona.edu/ebptoolkit
Cochrane Library http://cochranelibrary.com
National technical Assistance Center on Transition (NTACT): http://transitionta.org
Research and Training Center on Disability in Rural Communities: http://rtc.ruralinstitute.umt.edu
Rehabilitation Research and Training Center for Evidence Based Practice in Vocational Rehabilitation: http://research2vrpractice.org

Learning Exercises

Self-Check Questions

1. Explain how evidence-based practice (EBP) influences service policy.
2. What is the difference between "filtered" and "unfiltered" information? What does it mean for the practitioner?
3. Why are counseling and VR services considered to be behind other related fields in implementing EBP?
4. Draft an explanation for EBP that you might share with a client and/or family members, telling them about the process and the benefits.
5. Think of a clinical question that would assist you in your practice. Search the literature and see what kind of evidence you find.

Field-Based Experiential Assignments

1. Divide students into two groups, and have one group search for all individual articles supporting the practice of the working alliance and the other group search for a meta-analysis

of the same. Have the students discuss what they have discovered and why the meta-analysis provides stronger support.

2. Choose a review from the Cochrane Library and instruct the students, in groups, to review and discuss the merits and weaknesses of the literature used in the meta-analysis.
3. Students will collaborate in groups to identify a clinical question that is relevant in a given setting. Then, they will assess the literature to identify practices that are empirically supported for the situation. Finally, they will evaluate the quality of the support of the practices and determine which has the greatest empirical support.

Multiple Choice Questions

1. The RE-AIM model is a valuable framework for research that will contribute toward EBP because:
   (a) It requires that researchers stay broad enough so that findings will apply to everyone.
   (b) The "E" in the acronym means evidence.
   (c) Emphasis is on the target audience, and clearly defining the population and sample.
   (d) The model is not useful for EBP.
2. One of the most challenging aspects of applying EBP in rural practice is:
   (a) People in rural areas do not believe in EBP.
   (b) Research is typically not carried out within the rural context.
   (c) Rural counselors often have to work alone.
   (d) Caseloads in rural areas are much higher.
3. Participatory action research (PAR) is suggested as a useful approach to building EBP in rural communities because:
   (a) PAR requires that researchers work with practitioners to plan and execute studies.
   (b) PAR can only be done in rural settings.
   (c) PAR requires equal attention to rural and suburban areas.
   (d) PAR requires that researchers plan studies inclusive of all populations.
4. A major problem associated with the lack of EBP available for rural practitioners is:
   (a) Counselors have limited evidence to apply to clinical decisions.
   (b) Ethically, if there is no EBP, counselors cannot work with any clients.
   (c) Clients will be upset with the low quality of services provided.
   (d) Supervisors have to work twice as hard to help counselors.
5. What aspects of organizational culture might support counselors in learning more about EBP?
   (a) Strict requirements
   (b) Encouragement of innovation
   (c) Policy
   (d) Supervision
6. Knowledge translation (KT) is best defined as:
   (a) An iterative process that includes the synthesis of knowledge through empirical research and ethically sound application of information to improve outcomes
   (b) A process of identifying research findings and translating them into different languages to promote global information sharing
   (c) Knowledge sharing, including findings from different fields, as well as different cultures
   (d) A consultation process where the researcher comes to visit the agency and explains his or her latest study
7. One of the practices identified in the chapter that has shown promise in rural communities was:
   (a) Ride sharing programs
   (b) Agricultural initiatives
   (c) Dual relationships
   (d) Community navigators
8. External validity is best defined as:
   (a) The level of control the researcher has over the variables to rule out alternative explanations for findings.
   (b) The extent to which the findings are generalizable beyond the sample population.

   (c) The confidence the researcher has in the measures used.
   (d) How honest the researcher is while performing the study.
9. A strategy identified to help practitioners become more comfortable reading empirical studies was:
   (a) Tutoring sessions
   (b) Periodic testing
   (c) Study times
   (d) Journal clubs
10. In order to effectively use EBP as a clinical decision-making tool, what should the practitioner do once an intervention is selected?
   (a) Check the literature one more time.
   (b) Evaluate the effectiveness with this particular client.
   (c) Ask his or her supervisor.
   (d) Test an alternative hypothesis.

Key

1. C
2. B
3. A
4. A
5. B
6. A
7. D
8. B
9. D
10. B

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Erratum to: Disability and Vocational Rehabilitation in Rural Settings

Debra A. Harley, Noel A. Ysasi, Malachy L. Bishop,
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The Biography of the co-editor Dr. Noel A. Ysasi was incorrect in the originally published book and the revised biography is updated in the current version of the book to reflect in FrontMatter.

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