Third Edition

Autism Spectrum Disorders

Identification, Education, and Treatment

Edited by
Dianne Zager

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Pace University

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This book is dedicated with love and respect to my parents, Merylin Edelson and Edmond Edelson, M.D., who have instilled in me a love of learning, a commitment to family, and a dedication to human service. They have served as wonderful role models to their children and grandchildren, consistently exemplifying great moral and ethical integrity in combination with compassion and generosity. I continue to learn from and appreciate them.

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Contents

III: Educational Programming, Intervention, and Medical Treatment for Persons With Autism

Foreword

Autism, as a field, has undergone significant changes since the publication of the previous edition of *Autism: Identification, Education, and Treatment.* As the fastest growing developmental disability category, the autism spectrum has broadened to include individuals functioning across a wide range of cognitive abilities and behaviors. To highlight the intelligence, sophistication, and contributions to society of many persons on the autism spectrum, as well as to hear from a learned consumer herself, I have invited Dr. Temple Grandin to prepare the Foreword to this edition. Dr. Grandin is Associate Professor of Animal Science at Colorado State University. She is the author of *Thinking in Pictures.* Her words are unedited and enlightening.

***Foreword* by Temple Grandin**

The umbrella of the autism spectrum is very large. Children and adults on the spectrum range from nonverbal and severely handicapped to mild Asperger cases that may be in a talented and gifted program. Both research and practical experience has shown that young children diagnosed as having autism benefit greatly from early intense behavioral interventions. I was lucky to receive early speech therapy by age 2½. My speech teacher used many of the same applied behavior analysis techniques that are used by therapists today. My mother also hired a nanny who spent hours playing turn-taking games with me and my sister. My entire day was structured and I also had to behave at "Miss Manners" meals. I was a child of the 1950's and life was more structured. I was allowed to lapse back into autism for 1 hour after lunch and a half hour after supper. Often I would spend this time spinning a brass cover that covered up a bolt on the bed frame. My therapist and mother had to keep me connected to the world for many hours each week.

An intensive structured program that is appropriate for a child with full-blown autism symptoms at age 2 or 3 is not appropriate for an Asperger's

child that behaves like a "little professor" at an early age. This child needs teachers who will develop his or her talents into skills that can become a career. In my business designing livestock equipment, I interact with many engineers and technical people who are probably mild Asperger's. These are the happy people with Asperger's who have fulfilling work. The unhappy ones I see have no hobby or career to make life fulfilling.

I have observed that there are three factors that make an Asperger's person successful. They are: 1) development of talents, 2) mentor teachers in high school, college, or in the workplace, and 3) medication. I know several engineers in my field who take Prozac. I take antidepressants. Anxiety and nervous panic attacks would have destroyed my life. I was saved by antidepressants starting in my early thirties. Not all high functioning people with autism or Asperger's need medication, but many do. I would like to add a word of caution. People in the spectrum often respond best to very low doses of antidepressants.

There is too much emphasis in the education field on deficits and not enough emphasis on developing talents. People who are on the lower end of the spectrum can also benefit by activities or jobs that utilize their area of strength. Dr. Marcia Smith discusses some of her success in her chapter.

How can such a wide spectrum of people be in the Autism/Asperger continuum? In all of these people ranging from nonverbal to an Asperger's scientist there are problems with social relatedness. This is probably the core deficit in autism. Brain research by many investigators has shown that the parts of the brain that control emotions are abnormal or underdeveloped.

People on the spectrum, regardless of functioning level, have to learn social skills like being in a play. In my book *Thinking in Pictures*, I describe how I used previous experience and articles I had read about international diplomacy as templates for social interactions.

Lastly, all thinking by people on the spectrum goes from details to general principles. Lots of little details have to be linked together to make general principles. The more information I can put on my "hard drive" in my brain's computer, the better I can act. Being autistic is like never growing up. As I learn more, I keep on developing. I am constantly adding new information to my database. Social skills keep improving as more experiences are added that can serve as templates.

—Temple Grandin

Preface

The recent increase in the number of children being diagnosed as having autism spectrum disorders (ASD) and the current interest in the field of autism, have led to heightened demand for information by professionals, students, and parents. As the incidence of autism has grown, ASD has become a major special education category. Autism has been, and continues to be, the focus of extensive study and controversial debate. New research initiatives, specialized programs, and parent and professional organizations are receiving a great deal of media coverage. Much is happening in the field; many new advances have been made in medical and educational research.

The field of autism is currently, quite literally, experiencing growing pains. The astounding increase in diagnosed cases of ASD over the past several years raises concerns about diagnostic criteria, etiology, and availability of appropriate services. Perhaps the recently reported increase in the incidence of autism stems from a growing awareness and a new level of sophistication within the general public regarding this disorder. Or, perhaps we're seeing more cases because we have broadened the diagnostic criteria to include a wider range of ability levels and behaviors. A third and distinct possibility, however, is that, although there has indeed been a broadening of the diagnostic criteria for this disability category that has resulted in increased numbers of diagnoses, an actual rise in the number of classic *DSM-IV* cases of autism has occurred. Autism is more prevalent today than it was a few years ago. In the first chapter of this book, titled, "Definitions and Characteristics of the Spectrum," Joel Bregman, M.D., presents a thorough overview of ASD and a review of research related to the prevalence of the disorder.

Because more individuals (with a wide array of characteristics, ability levels, and types of service needs) are receiving diagnoses of autism, this new edition, now called *Autism Spectrum Disorders: Identification, Education, and Treatment*, has altered its focus. Authors who contributed to the two

earlier editions have revised and updated their chapters, incorporating into their work the significant advances of the filed. Readers are brought up to date on past, present, and emerging directions in educational approaches for students with autism in V. Mark Durand's chapter.

This third edition includes information on diagnosis and intervention for individuals across the autism spectrum. New information in the areas of research, education, and intervention approaches are examined and discussed. In a new section, entitled "The Early Years," Jack Scott and Wanda L. Baldwin describe in detail options and challenges in intensive early intervention. Elaine Gabovitch and Nancy D. Wiseman provide information on early identification that should prove helpful to physicians, parents, and other caregivers.

Another difference in the new text is the increased attention devoted to parents and families. In addition to the chapter by Anton Hecimovic and Susan Gregory on the evolving role of families, a new chapter by Judith S. Bloch, Joan Weinstein, and Martin Seitz has been included to address the needs of families of young children during the preschool years.

Some of the earlier chapters have been omitted or combined with others. For example, the chapter by Raymond Romanczyck et al. dealing with myths and controversies in autism has been omitted. In its place, Dr. Romanczyck and Jennifer M. Gillis review current approaches, examining what works, what does not work, and how to make informed decisions considering these differences.

Neurobiological research and medical treatment are covered by Luke Y. Tsai, M.D., who presents information on new research and advances in treatment. The chapter on medical treatment was written especially for parents and other caregivers of persons with autism to help them gain knowledge of when and how medications can be employed as part of the comprehensive treatment of this disorder.

Jan S. Handleman and Lara M. Delmolino have revisited the area of assessment. They discuss current tools and approaches to the educational assessment of children with autism. Behavioral strategies for building social competence are explored in the chapter by Richard Simpson and Kaye Otten. Amy M. Wetherby and Barry M. Prizant share their combined clinical and research-based knowledge on guidelines to assessment and intervention for communication and language development. Instructional methodological concerns and strategies for educating children with autism are described in the chapter, "Teaching Students With Autism Spectrum Disorders." Marcia Datlow Smith and Leslie R. Philippen explore current trends in community integration and supported employment for adults with autism.

The contributing authors have done an outstanding job with the difficult task of integrating older established approaches with advances of

recent years to present a current picture of the field of autism today and a vision for the future. The tone of the text is practitioner- and parent-friendly, while still being grounded in research and theory. This edition should prove helpful to a wide audience of professionals, parents, and students.

—Dianne Zager

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Contributors

Wanda L. Baldwin, M.S.W. LCSW St. Mary's Hospital, West Palm Beach, Florida

Judith S. Bloch, M.S.W. Variety Child Learning Center, Soysset, New York

Joel D. Bregman, M.D. Center for Autism, North Shore—Long Island Jewish Health System, Bethpage, New York

Lara M. Delmolino, Ph.D. Douglass Developmental Disabilities Center, New Brunswick, New Jersey

V. Mark Durand, Ph.D. University of South Florida, St. Petersburg, Florida

Elaine M. Gabovitch, B.A. First Signs, Inc., Lexington, Massachusetts

Jennifer M. Gillis, M.A., B.C.A.B.A. Institute for Child Development, State University of New York at Binghamton, Binghamton, New York

Temple Grandin, Ph.D. Colorado State University, Fort Collins, Colorado

Susan Gregory, Ph.D. Montana State University, Billings, Montana

Jan S. Handleman, Ed.D. Douglass Developmental Disabilities Center, New Brunswick, New Jersey

Anton Hecimovic, Ph.D. Montana State University, Billings, Montana

Kaye Otten, Ph.D. University of Kansas, Kansas City, Kansas

Leslie R. Philippen, M.A. Community Services for Autistic Adults and Children, Rockville, Maryland

Barry M. Prizant, Ph.D., CCC-SLP Childhood Communication Services, Cranston, Rhode Island

Raymond G. Romanczyk, Ph.D. Institute for Child Development, State University of New York at Binghamton, Binghamton, New York

Jack Scott, Ph.D., BCBA Florida Atlantic University, Boca Raton, Florida

Martin Seitz, ACSW Adelphi University, Garden City, New York

Nancy Shamow, Ph.D. Ascent School for Autism, Deer Park, New York

Richard Simpson, Ph.D. Kansas University Medical Center, Kansas City, Kansas

Marcia Datlow Smith, Ph.D. Community Services for Autistic Adults and Children, Rockville, Maryland

Luke Y. Tsai, M.D. University of Michigan Medical School, Ann Arbor, Michigan

Joan Weinstein, ACSW Variety Child Learning Center, Syosset, New York

Amy M. Wetherby, Ph.D. Florida State University, Tallahassee, Florida

Nancy D. Wiseman, B.S. First Signs, Inc., Merrimac, Massachusetts

Dianne Zager, Ph.D. Pace University, New York, New York

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Part I

THE STUDY OF AUTISM

PERSPECTIVES OF A FIELD IN TRANSITION

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Chapter 1

Definitions and Characteristics of the Spectrum

Joel D. Bregman
North Shore-Long Island Jewish Health System
Yale Child Study Center

OVERVIEW OF THE AUTISM SPECTRUM

Conception of the Autism Spectrum

Autism and the pervasive developmental disorders (PDDs) are highly complex and variable in their clinical presentation and manifestations. For example, symptoms and characteristics change with developmental maturity and vary with the degree of associated cognitive impairment (Filipek et al., 1999a). This evolving pattern of clinical features can make the differential diagnostic process very difficult in some cases. Nonetheless, the defining feature of autism is the presence of a distinctive impairment in the nature and quality of social and communicative development (influenced by the specific biological and environmental circumstances of the individual). It is this impairment that distinguishes autism from other neurodevelopmental conditions (e.g., mental retardation, developmental language disorders, specific learning disabilities). For example, whereas mental retardation is characterized by a pervasive developmental delay, autism is characterized by a distinctive impairment in the nature of social-communicative development. The prognostic significance of this autistic social dysfunction is underscored by preliminary studies that report a negative correlation between the severity of this social impairment and treatment responsiveness,

at least with regard to social and linguistic growth following intensive, behaviorally based early intervention (Ingersoll, Schreibman, & Stahmer, 2001).

Additional complexity in the differential diagnosis of autism and related PDDs results from a wide range of accompanying abnormalities within cognitive, adaptive, affective, and behavioral domains of development, including mental retardation (Volkmar, Cook, Jr., Pomeroy, Realmuto, & Tanguay, Volkmar & Klin, 1999), deficits in executive functions (Liss, Fein, et al., 2001; Ozonoff, 1995, 1997; Pennington et al., 1997), limitations in adaptive skills (especially in socialization and functional communication; Liss, Harel, et al., 2001), learning disabilities (e.g., nonverbal learning disability; Rourke, 1995), mood instability (Di Martino & Tuchman, 2001; Hellings, 1999; Hollander, Dolgoff-Kaspar, Cartwright, Rawitt, & Novotny, 2001), stereotypic and self-injurious behaviors (King, 2000), anxiety disorders (Kim, Szatmari, Bryson, Streiner, & Wilson, 2000), and aggression (Hollander et al.; King, 2000).

The Broader Autism Spectrum

During the past decade, the reported prevalence of autism-related conditions has risen markedly (Bryson, Clark, & Smith, 1988; Fombonne, Du Mazaubrun, Cans, & Grandjean, 1997; Fombonne, Simmons, Ford, Meltzer, & Goodman, 2001; Wing & Potter, 2002; Yeargin-Allsopp et al., 2003), in part as a result of a broadening of the diagnostic concept to include milder and more atypical variants. This has led to the increasingly frequent use of the term *autism spectrum disorder* (ASD) within clinical and educational settings (Filipek et al., 1999b), consistent with prior conceptions of autism, including the broader autistic spectrum (Wing & Gould, 1979) and ASD (Allen, 1988).

Recent genetic studies lend support to this concept, because it appears that the heritable factor in autism is not the specifically defined disorder itself, but rather, subtle weaknesses in social interaction and interpersonal discourse (Bailey, Palferman, Heavey, & Le Couteur, 1998; Le Couteur, Bailey, Goode, Pickles, et al., 1996). The literature suggests that the genetic liability for autism may be associated with limited interest in social interaction, few close confiding friendships, impaired socioemotional responsivity (a less robust finding), language delays, conversational impairments, problems in communication planning, and possibly anxiety and rigidity (Bailey et al., 1998). The boundaries of the behavioral phenotype for autism has been examined in same-sex twin pairs (28 monozygotic [MZ] and 20 dizygotic [DZ]), one of whom had autism (Le Couteur et al., 1996). Among the discordant co-twins (those *without* autism), findings included language

impairments in childhood and social deficits persisting into adulthood. This broader phenotype was much more common among MZ pairs than DZ pairs, indicating a strong genetic influence. Behavioral and cognitive characteristics of autism appear to be less genetically based because no differences were found within and between MZ twin pairs.

Family and case control studies of community-ascertained probands with autism support the broader autism phenotype (BAP) concept (Folstein et al., 1999). These investigators identified a subset of autism family members manifesting a language component of the BAP (separate from the social component). This is consistent with the hypothesis that several independently segregating genes (i.e., those that have distinguishable manifestations) interact to cause autism (Folstein et al., 1999). Dawson and colleagues propose that the identification of autism susceptibility genes will be strongly influenced by success in characterizing dimensional attributes of broader phenotype autism traits (Dawson et al., 2002). These investigators have hypothesized that six traits characterize this broader phenotype, namely, (a) face processing, (b) social affiliation or responsiveness to social reinforcement, (c) motor imitation, (d) memory for social–emotional stimuli, (e) executive functioning (e.g., planning and flexibility), and (f) language ability (e.g., phonology).

However, in considering the BAP, it is important to keep in mind that this is not synonymous with the diagnostic entity of autism or ASD, itself. Rather, it represents a genetically determined set of personal characteristics that increases the susceptibility of offspring to the development of the clinical syndrome. This is similar to a large number of clinical conditions that are influenced by susceptibility genes, such as certain types of malignancies, cardiovascular disease, and so forth. The presence of these susceptibility genes does not automatically result in the actual disorder; rather, it increases the likelihood that future generations will develop the clinical condition. Therefore, a "carrier" of these susceptibility genes should not be diagnosed as manifesting autism or ASD.

Several methodological issues are present both within and across studies of the BAP that complicate the interpretation of reported findings (Bailey et al., 1998). For example, there is a good deal of heterogeneity among probands with regard to PDD subtype (e.g., autistic disorder vs. Asperger syndrome [AS] vs. PDD not otherwise specified [NOS]), diagnostic criteria (e.g., edition of *DSM* or *ICD* used), and the presence of known medical and co-morbid neuropsychiatric conditions. In addition, there are differences across studies with regard to the subject ascertainment procedures employed (e.g., epidemiological or consecutive case); the nature of control subjects, if any (e.g., other genetic conditions or developmental disabilities); and the relatives that were studied (e.g., siblings, parents, and cousins) (Bailey et al., 1998).

HISTORICAL PERSPECTIVE

Current conceptions of the clinical syndrome of autism are direct extensions of the work of Leo Kanner, Hans Asperger, and Michael Rutter. Classic autism (or Kanner syndrome) is the prototypical ASD, representing the PDD subtype that involves the most severe social–communicative impairments and the greatest number and range of clinical characteristics. The essential features of Kanner syndrome are most closely captured by the *DSM-IV* and *ICD-10* PDD subtypes of autistic disorder and childhood autism, respectively.

In his seminal paper published in 1943, Leo Kanner carefully described a unique neurodevelopmental condition (which he termed *early infantile autism*) that appeared to result from a congenital inability to form close affective ties with others and to tolerate minor changes in the environment and in daily routines (Kanner, 1943). He also described what he considered to be secondary characteristics, including speech and language abnormalities (e.g., delays, unusual intonation, echolalia, pronominal reversal, and perseveration), uneven cognitive development, repetitive behaviors, and unusual sensitivities. Kanner was struck by the unique nature of the social and affective impairments manifested by his cohort of patients with autism, viewing them as fundamentally different from the problems in social and emotional functioning experienced by his patients with more common neuropsychiatric conditions.

A year later, in 1944, Hans Asperger, a Viennese physician, published a paper in the German literature in which he described four children who also manifested a striking impairment in social relatedness, yet who had sophisticated linguistic skills, good problem-solving abilities, and intense yet restricted patterns of interest (Asperger, 1944). However, knowledge of Asperger's work did not become widespread until the 1980s, following the publication of Wing's case studies and discussions of the syndrome (Burgoine & Wing, 1983; Wing, 1981).

Despite knowledge and clinical experience, a diagnostic category for autism and related disorders was not introduced until publication of the third edition of the *Diagnostic and Statistical Manual* (*DSM-III*) in 1980 (American Psychiatric Association [APA], 1980). Until that time, autism was classified under the psychotic conditions, most notably childhood schizophrenia. By the end of the 1970s, it was clear that autism was a unique condition, separate from schizophrenia in terms of genetics, clinical manifestations, and course. The diagnostic criteria that were adopted in the *DSM-III* reflected those identified originally by Kanner and expanded by Rutter in the mid- to late-1970s (Rutter, 1974, 1978, 1979), which highlighted an early onset, impairments in social relatedness, atypical language forms and usage, as well as unusual resistance to change and stereotyped, ritualistic patterns of

behavior. Thus, the first diagnostic category for autism reflected the classical early concept. As such, it was highly specific and overly narrow.

In the *DSM-III,* two other categories were included under the *pervasive developmental disorder* label (a diagnostic term coined to indicate what are now considered to be ASDs), including childhood onset pervasive developmental disorder (which was soon dropped because of questionable validity), as well as an atypical category (which included cases of autistic social dysfunction that did not meet full criteria for autistic disorder). A growing recognition that the *DSM-III* conception of autism was overly narrow resulted in a modification of the PDD criteria, which were field tested in the mid-1980s. This culminated in the publication of a revised edition in 1987 (*DSM-III-R*). This edition of the *DSM* included two PDDs, namely, autistic disorder and PDDNOS. However, it soon became obvious that the *DSM-III-R* criteria were overly inclusive, blurring the boundaries between autism and other conditions that shared some clinical features but differed from autism regarding the nature of the social and communicative impairment. Therefore, the criteria were revised and field tested again, culminating in the publication of the fourth edition of the *DSM* in 1994 (*DSM-IV*). A major advance at that time included the adoption of a highly similar set of criteria by both the *DSM-IV* and the International Classification of Diseases (*ICD-10*).

Based on current conceptions, the primary clinical symptomatology of the PDDs (i.e., ASDs) falls within three major categories, namely, (a) qualitative impairment in social interaction; (b) impairments in communication; and (c) restricted, repetitive, stereotyped behavior, interests, and activities. The following discussion of clinical characteristics is based on the prototypical ASD—autistic disorder (*DSM-IV,* 1994)/childhood autism (*ICD-10,* 1992, 1993). For the purpose of this discussion, the terms *autistic disorder* and *autism* are used synonymously. The unique features of the other recognized PDDs are discussed in a following section.

CLINICAL CHARACTERISTICS

Qualitative Impairments in Social Interaction

Within the social domain, the central features of autism include impairments in social reciprocity (the give and take of social interaction); the integration of verbal with nonverbal aspects of social discourse; the development of selective friendships; and the sharing of excitement, interests, and enjoyment with others (Filipek et al., 2000; Volkmar et al., 1999; Volkmar & Klin, 1999). From the first months of life, impairments are present in social reciprocity and social communication. Infants and toddlers with autism

make meaningful eye contact and attend to the voices and faces of others less often than their typically developing peers. Responsive smiling may be absent, and social imitative games (e.g., peek-a-boo, so big, and pat-a-cake) may be largely one sided. In addition, toddlers with autism engage less often in social referencing and joint attention, rarely sharing observations, excitement, and achievements with others in a reciprocal fashion (through the integration of speech, vocalizations, reciprocal eye contact, pointing, facial expressions, and gestures). Although they may label or point out something of interest, they typically do not utilize this as a springboard for a give-and-take interaction with others. They may not make reciprocal eye contact as they point and vocalize; monitor the reactions of others to gauge interest, enthusiasm, and approval; or demonstrate curiosity about the interests, preferences, opinions, and experiences of others. When in the midst of stimulating social activity, they may prefer to explore their inanimate environment or engage in a perseverative interest or behavior.

Evidence supporting the presence of early social deficits is accruing from studies of home-videotape recordings filmed prior to the recognition of autism (Bernabei, Camaioni, & Levi, 1998; Osterling, Dawson, & Munson, 2002), as well as from prospective studies of very young children using standardized assessment tools (Baron-Cohen, Cox, Baird, Sweettenham, & Nightingale, 1996; Lord, 1995). For example, in a study of 1-year-olds, raters "blind" to subject group membership found that children later identified as manifesting ASD looked at others and oriented to their names less frequently than did infants with mental retardation and typical social development (Osterling et al., 2002). This represented a finding specific for autism, because the groups with ASD and mental retardation did not differ from each other with regard to the presence of other behaviors (e.g., gesturing and looking at objects held by others, engaging in repetitive motor actions), although both groups *did* differ from their typically developing peers. In another study, the absence of social smiling and appropriate facial expressions by 1 year of age were predictive of autism (Adrien et al., 1993).

Bernabei et al. (1998) conducted a videotape study that utilized an observational checklist targeting social interaction, communication, and both functional and symbolic play. The investigators reported that 1.8- to 4.6-year-old infants and toddlers who were later diagnosed with autism/PDD rarely made communicative gestures, played imaginatively, or participated in conventional social games (Bernabei et al., 1998). However, they did demonstrate mutual attention, attachment behaviors, emotional reactions, and vocalizations, although the degree of reciprocity with which they did so is unclear.

Baranek (1999) analyzed videotapes retrospectively and found that 9- to 12-month-olds later diagnosed with autism exhibited impairments in visual

orientation, sensitivity to tactile stimulation, and limited responsiveness to name, in contrast with typically developing children and those with developmental delays (Baranek, 1999).

In a prospective study, 16,000 eighteen-month-olds were screened by primary care clinicians using the Checklist for Autism in Toddlers (CHAT). Eighty-three percent (83.3%) of the 12 toddlers who failed the items of protodeclarative pointing, gaze-monitoring, and pretend play were later diagnosed with autism (confirmed on reassessment at 3½ years of age) (Baron-Cohen et al., 1996). Protodeclarative gestures are used for the purpose of sharing observations and experiences with others, whereas protoimperative gestures are used to direct the behavior of others (generally to fulfill requests or needs). In a longitudinal study, Lord (1995) found that 2-year-old children who failed to make appropriate gains in social skills and who engaged in repetitive behaviors were at significant risk for the development of autism by 3 years of age. Utilizing valid and reliable interview and observational instruments, Lord found that deficits in two specific social–communicative areas were highly predictive of autism, namely, showing behavior (joint attention) and responsiveness to one's name being called.

Children with autism observe, imitate, approach, and interact with their age-mates less often than do typically developing peers. In social settings (e.g., play groups, infant–toddler programs, preschool classes, and family gatherings), they tend to remain on the periphery of social activity, respond solely to adults, or engage other children in one-sided physical or highly scripted play (in which they direct the action). They may exhibit a precocious aptitude for early academic tasks and an avid interest in exploring the details of the inanimate world around them, yet fail to understand or derive pleasure from imaginative and interactive play. When older, they generally prefer spending their time amassing factual knowledge on narrow, esoteric topics rather than playing creatively with other children, participating in social events, or joining clubs and athletic teams. Their interests often revolve around taxonomy, classification, and categorization. Although they may enjoy participating in chess tournaments, *Star Wars* memorabilia auctions, or Pokemon and Magic Card swaps, they typically do not enjoy "hanging out" with peers, discussing favorite teams, music, and clothing, or attending sports events or concerts.

Adolescents and young adults with autism may fail to demonstrate basic social etiquette, understand social intent; appreciate subtle emotional states within themselves and others; or predict the thoughts, feelings, and behavior of others even in relatively straightforward social situations. They may ask unusual, overly personal, or rhetorical questions in order to obtain factual information related to an esoteric interest; seek repeated reassurance over a minor issue, or awkwardly attempt to demonstrate friendliness. Statements

may be made that are experienced by others as highly provocative, curt, or insensitive, when this is not the intent. Highly literal and concrete problem solving can lead to socially inappropriate comments and behavior, with little appreciation of the need to consider extenuating circumstances, exceptions to the rule, or the unique needs and preferences of others.

Qualitative Impairments in Communication

Within the communication domain, impairments are present in a number of linguistic and nonverbal areas, the most fundamental of which are pragmatics and semantics (i.e., the social usage and explicit or implicit meaning of language and gestures). Although linguistic capability varies greatly across the spectrum (from a total absence of speech to highly sophisticated and erudite language), significant impairments in pragmatics and semantics are universal among individuals with ASD. They communicate primarily to express needs, desires, and preferences, rather than to convey sincere interest in others, or to share experiences, excitement, and feelings. Even among those possessing highly sophisticated and complex language, compliments, words of empathy, and expressions of joy in the good fortune of others are very rare. There is little reciprocity, mutuality, or shared purpose in discussions. In addition, speech and gestural forms of communication are poorly integrated, often resulting in awkward and uncomfortable social interactions. Implicit, subtle, and indirect communications are neither used nor perceived. Expressive communication tends to be explicit, direct, and concrete. During discussions, persons with autism often fail to prepare their speaking partners for conversational transitions, new topics, or personal associations. This can result in digressive, circumstantial, and tangential comments and discussions. It would appear as though persons with autism assume that others are implicitly aware of their experiences, viewpoints, attitudes, and thoughts.

The fashion in which these deficits are manifest is influenced by age, overall cognitive level, temperament, and the presence of sensory or physical limitations. In toddlers, for example, impaired pragmatics may be manifested by significant limitations in reciprocal eye contact, *responsive* smiling, joint attention (mutual sharing of interests and excitement), and social imitative play. In addition, socially directed facial expressions, instrumental and emphatic gestures, and modulation of speech prosody (intonation, cadence, and rate) are rarely used to complement speech, communicate feelings and attitudes, or moderate social discourse. Among preschool children, impairments in symbolic functioning (e.g., language) are accompanied by serious limitations in pretense (e.g. symbolic, imaginative, creative, and interactive play).

In contrast, pragmatic impairments among adolescents with Asperger syndrome may be manifested by one-sided, pedantic discussions, with no attempt to involve speaking partners by acknowledging and integrating *their* experiences, ideas, and viewpoints into conversations. Sincere attempts by others to engage in reciprocal conversations may be met with a lack of acknowledgment, annoyance, and disinterest. Comments or questions that are "snuck in" by the listener may be experienced as rude interruptions, prompting the directive, "Wait! I'm not done talking yet." The result is a monologue or lecture that often includes abrupt changes of topic and the introduction of unexplained personal associations. This lack of conversational reciprocity suggests that persons with AS and high-functioning autism (or HFA) inherently assume that the listener is implicitly aware of their own experiences, viewpoints, and intent.

Because the relaying of factual and concrete information is the primary goal of "social" dialog among those with ASD, the communication of subtle attitudes, viewpoints, and emotions (particularly secondary emotions, such as embarrassment, guilt, and envy) are largely irrelevant and superfluous. Therefore, emphatic gestures, informative facial expressions, and vocal modulation lack essential meaning for them. The result is that persons with autism generally disregard nonverbal cues and fail to incorporate them into their own discussions. Because this component of social communication often conveys essential information regarding feelings, attitudes, and opinions, an inability to identify, interpret, and produce nonverbal cues can have a highly detrimental effect on social interactions and relationships. Given these impairments, it is not surprising that verbal and nonverbal aspects of communication are poorly integrated, and that subtlety and nuance are rarely conveyed.

Figurative and inferential language is another area of communication that is impaired in autism, largely due to a combination of deficits in abstract and conceptual thought, social reciprocity, and appreciation of the subtleties of social communication. Persons with ASD are highly literal and concrete in their language and thought processing, typically failing to understand metaphor, irony, sarcasm, and facetiousness. As a result, comments are often misinterpreted and discussions misunderstood. In addition, in an effort to remain true to the facts, comments and questions are often presented in an overly direct, straightforward, and "brutally honest" manner, lacking appropriate tact and sensitivity. This can cause embarrassment and distress for the listener and confusion for the speaker with AS or HFA. Both may become angry and resentful; the listener, because of emotional distress and perceived mistreatment; the speaker, because of the seemingly unjustifiable overreaction and a negative attitude displayed by the listener. From the perspective of the person with AS or HFA, the listener responded in a rude and ungrateful manner to comments that were intended to be

informative, useful, and corrective. The emotional distress, embarrassment, and attack on self-esteem experienced by the listener are relatively foreign to the individual with autism. Interestingly, principles, rules, and codes of behavior can be interpreted in a highly concrete and rigid manner. This can result in insensitive and hurtful comments and behavior, because exceptions to the rule, adjustments to unexpected social contingencies, and appreciation for the spirit (not simply the letter) of the law are relatively foreign to those with autism. There is little awareness that rigid adherence to unavoidably flawed rules can result in a situation that is antithetical to the underlying intent of the rule itself. (For example, someone with AS might argue that in order to respect and honor flag and country, persons with paralyses should be barred from attending public events that include the singing of the national anthem, because they would be unable to stand respectfully, as generally expected.)

Abnormalities in other aspects of speech and language are also influenced by the social deficits of autism. For example, modulation of speech prosody (e.g., intonation, inflection, and cadence) can be very powerful in conveying feelings, attitudes, and impressions. However, because emotions, social self-esteem, and admiration are not fully appreciated or experienced by those with ASD, it is not surprising that the social modulation of speech prosody is either absent or so exaggerated that insincerity and distain are conveyed (even when this is not the intent). In addition, a lack of appreciation for reciprocity, mutuality, and the distinction between statements and questions may contribute to such features of autism as echolalia, scripted phrases, and a question-like intonation when making comments. (What better way to accurately relate data and factual information than to produce an exact duplicate of the statements and writings of others, replete with the faithful preservation of pronouns, tense, and intonation).

Restricted, Repetitive, and Stereotyped Patterns of Behavior, Interests, and Activities

Within the sensory and behavioral domains, developmentally immature and atypical perceptions, reactions, and behaviors occur. For example, many children with autism continue to experience the proximal senses of touch, taste, and smell as highly salient long after they have become overshadowed by the distal senses of sight and hearing among typically developing children. This might account for the predominance of olfactory, tactile, and oral forms of exploration among some children and adolescents with autism. In some cases, the salience of proximal sensation persists well into adulthood.

Another sensory feature is hypersensitivity to various stimuli (auditory, tactile, visual, and olfactory). Even low-intensity exposures can result in

distress, agitation, and discomfort. Such unexpected reactions may convey the impression of physical pain or a marked overload of the central nervous system pathways responsible for modulating and neutralizing excessive stimulation (both negative and positive).

One of the defining features of autism and Asperger syndrome (as conceived by Kanner and Asperger) is that of rigidity and inflexibility in response to minor change and transition in the environment and daily routines. This insistence on sameness and invariance can be highly impairing, because the precipitants of these reactions often are of little social significance and do not disturb the smooth functioning of the social world. It is as though persons with autism depend on these inanimate markers of space and time because the social priorities that typically direct schedules and routines have little meaning and significance for them.

A range of repetitive stereotyped, compulsive, and ritualistic behaviors occur in autism, although no one behavioral symptom or symptom cluster is present among the majority of individuals. Compulsive behaviors include ordering and rearranging, ritualistic patterns of walking and pacing, repetitive actions (e.g., turning on and off lights, mechanical devices, and electronic equipment), and insistence on keeping all doors or cabinets closed. Stereotypic movements also occur in ASD (particularly among those with classic autism accompanied by significant cognitive impairment). A variety of different movements can be present, such as hand and arm flapping, toe walking, repetitive jumping, head shaking and weaving, and side-to-side rocking.

Interests and preferred activities are generally narrow and restricted. Among those with more classic forms of autism, a great deal of sensory exploration may occur, often involving minor details or parts of toys and objects. Often there is a fascination with subtle physical characteristics of toys and objects, such as texture, shading, and hue. The relationship among the parts of objects may also be of interest, such as the manner in which moving parts rub against one another or the distance that objects maintain from one another when they are spun independently. Exploration using combined senses also occurs, such as the intense visual scrutiny of light diffraction patterns as a prismlike stone is twirled in the sunlight. There also appears to be an apparent dissociation between the parts and the whole. Children and adults with autism often seem to be unaware of the significance and relevance of the whole toy or object (functional, symbolic, and emotional). Individuals with AS (less often with HFA) pursue highly restricted, nonfunctional, and often unusual interests, pastimes, and preoccupations. Factual information, concrete perceptions, and the processes of classification, categorization, and taxonomy are of particular interest and importance. Depending on the cognitive level, reading ability, and motivation of the individual, these interests can involve complex, detailed topics on which a great deal of time is

spent memorizing facts, numbers, and visual patterns. In AS, these intense preoccupying interests can include such topics as the exhaustive categorization of water heaters, downspouts, highway guardrails, meteorological forecasts, television program ratings, architectural styles and details, and battle formations over the centuries. Such individuals literally can become world experts on such topics, yet resist suggestions to transform this interest and knowledge into functional, meaningful, or marketable skills. The sole appeal seems to be the very process of memorization, categorization, and classification.

DIAGNOSIS AND CLASSIFICATION

Overview

The process of accurate diagnosis and classification is an essential endeavor in medicine, because it is key to ensuring validity and reliability, enabling etiological research, and identifying effective methods of treatment. Although ASDs are not medical illnesses in the classical sense, they do result from neurodevelopmental abnormalities that affect social, communicative, and behavioral functioning in fundamental ways. Our current state of knowledge indicates that autism is not a unitary condition with a single etiology, pathogenesis, clinical presentation, and treatment approach; rather, it is a group of related conditions that share many clinical features and underlying social–communicative impairments. The fundamental purpose of arriving at an accurate diagnosis is to promote meaningful research that will eventually lead to effective treatment and an ultimate cure. Accurate diagnosis also enables investigators, clinicians, educators, and parents to communicate clearly, effectively, and efficiently. Ideally, a valid and reliable diagnosis should convey a great deal of information about developmental strengths and weaknesses, short- and long-term prognosis, and treatments that are most likely to be effective. Both basic and applied research endeavors are enhanced by improvements in diagnosis and classification. Unfortunately, some would argue that categorical diagnosis results in stigmatization, reductionistic thinking, and in some cases, discriminatory practices. However, this need not be the case.

Early Screening and Diagnosis

During recent years, efforts have been made to identify ASD as early in life as possible, in order to begin implementing educational and treatment interventions; providing families with education, support, and community

resources; and reducing the stress and anxiety families experience as a result of incorrect or misleading diagnoses (Filipek et al., 1999). The importance of an early diagnosis is supported by findings of improved linguistic, cognitive, and adaptive functioning as a result of intensive early intervention (Harris & Delmolino, 2002; Pelios et al., 2001; Pelios & Lund, 2001; Rogers, 1998; Schreibman, 2000).

Studies have begun to appear in the research literature assessing the reliability and stability of autism diagnoses made during the early preschool years. Experienced clinical investigators have demonstrated that an accurate diagnosis of autism can be made in the second and third years of life. However, accuracy depends on the completion of a comprehensive, interdisciplinary assessment, one that includes the use of standardized diagnostic instruments in conjunction with clinical expertise (Charman & Baird, 2002). Nonetheless, even among experienced clinicians and investigators, false positive and false negative diagnoses are sometimes made. Within this age group, the most difficult diagnostic distinction is between autism and developmental language disorders (Charman & Baird, 2002). Diagnosis of the broader range of ASD is less reliable, as has been found for older samples (Klin, Lang, Cicchetti, & Volkmar, 2000; Mahoney et al., 1998; Volkmar et al., 1994). In particular, less severe ASD presentations may be misdiagnosed as developmental or language delay in very young children.

Investigators have begun to examine clinical variables that may be predictive of treatment response and general prognosis. For example, Ingersoll et al. (2001) found that preschool children with autism who exhibited low baseline levels of social avoidance experienced significantly more social and linguistic progress than did their high-avoidance counterparts following 6 months of intensive incidental teaching and pivotal response training (provided in an inclusive setting).

Pervasive Developmental Disorder Subtypes

Although the field of autism has not lacked for controversy regarding diagnostic criteria and the boundaries of autism and related disorders, these conditions are among the most reliably diagnosed and validated conditions in all of neurodevelopment and psychiatry. With that said, there is much to be learned about this spectrum, given its enormous complexity.

During the past several decades, a great deal of progress has been made in the area of diagnosis and classification of autism and related pervasive developmental disorders. This has been the result of intellectual curiosity, clinical dedication, and the ever-increasing sophistication of biomedical research, clinical practice, and education. In the specialty of neuropsychiatry, much progress has been made in the area of differential diagnosis. With

TABLE 1.1
Comparison of *DSM-IV* and *ICD-10* Diagnostic Criteria

DSM-IV Diagnoses	*ICD-10 Diagnoses*
Autistic Disorder	Childhood Autism
Asperger's Disorder	Asperger's Syndrome
Disintegrative Disorder	Other Childhood Disintegrative Disorder
Rett's Syndrome	Rett's Disorder
Pervasive Developmental Disorder Not Otherwise Specified	Atypical Autism Other Pervasive Developmental Disorders Pervasive Developmental Disorders, Unspecified
Not Recognized	Overactive Disorder Associated With Mental Retardation and Stereotyped Movements

the publication of the first editions of the *Diagnostic and Statistical Manual* (published by the APA) and the *International Classification of Diseases* (published by the World Health Organization), the process of reliable and valid diagnosis was begun. A major accomplishment of *DSM-IV* and *ICD-10* has been general agreement in regarding the subtypes and criteria for the pervasive developmental disorders (see Table 1.1). Although some differences are present in the number and nature of PDD subtypes included under these two diagnostic systems, criteria for the autism proper, Asperger syndrome or disorder, Rett's syndrome or disorder, and childhood disintegrative disorder are essentially identical. This represents a major advance, because the international community can communicate using similar diagnostic criteria and conducting research investigations collaboratively.

The subtypes and criteria for the *DSM-IV* PDDs can be found in Tables 1.2 to 1.6. The characteristics of autistic disorder have been described previously, and the specific diagnostic criteria for this prototypical PDD are presented in Table 1.2. In this section, the other officially recognized PDD subtypes are discussed, in addition to disorders and syndromes that share some clinical features of PDD but do not involve a true autistic social dysfunction.

Asperger's Disorder

The validity of AS as a diagnostic entity distinct from HFA remains unproven (Klin & Volkmar, 2003; Klin, Volkmar, Sparrow, Cicchetti, & Rourke, 1995; Ozonoff & Griffith, 2000). Although some investigators have presented data in support of this diagnostic distinction (Klin et al.; Lincoln, Courchesne, Kilman, Elmasian, & Allen, 1988), others have not (Miller & Ozonoff, 2000; Szatmari et al., 1995). The lack of consensus is due, in part, to disagreement regarding the clinical characteristics that define AS; a subject of ongoing debate and research. As described by Asperger, the central

TABLE 1.2
DSM-IV Diagnostic Criteria for Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3)
  (1) Qualitative impairment in social interaction, as manifested by at least two of the following
    (a) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
    (b) Failure to develop peer relationships appropriate to developmental level
    (c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
    (d) Lack of social or emotional reciprocity
  (2) Qualitative impairment in communication, as manifested by at least two of the following
    (a) Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
    (b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
    (c) Stereotyped and repetitive use of language or idiosyncratic language
    (d) Lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level
  (3) Restricted repetitive and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following
    (a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal either in intensity or in focus
    (b) Apparently inflexible adherence to specific nonfunctional routines or rituals
    (c) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
    (d) Persistent preoccupation with parts of objects
B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (a) social interaction, (b) language as used in social communication, or (c) symbolic or imaginative play
C. Disturbance is not better accounted for by Rett's disorder or by childhood disintegrative disorder

clinical feature of the condition he named autistic psychopathy is a serious qualitative impairment in social reciprocity, manifested by either social isolation or atypical, one-sided interactions that lack fluidity, sensitivity, and adequate awareness of the unique viewpoints, feelings, and attitudes of others (Asperger, 1944). Those with AS fail to appreciate the significance of nonverbal social cues, social intent, the depth and range of feeling states, and the emotional impact that comments and behavior can have on others (Klin, Schultz, Rubin, Bronen, & Volkmar, 2001; Shamay-Tsoory, Tomer, Yaniv, & Aharon-Peretz, 2002). Although less socially withdrawn and avoidant than children and adults with classic autism, their social interactions are one sided and lacking in adequate reciprocity.

TABLE 1.3
DSM-IV Diagnostic Criteria for Asperger's Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following
   (a) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
   (b) Failure to develop peer relationships appropriate to developmental level
   (c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
   (d) Lack of social or emotional reciprocity
B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following
   (e) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal either in intensity or in focus
   (f) Apparently inflexible adherence to specific nonfunctional routines or rituals
   (g) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
   (h) Persistent preoccupation with parts of objects
C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning
D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years)
E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood
F. Criteria are not met for another specific PDD or for schizophrenia

According to *DSM-IV* criteria, the diagnosis of AS cannot be made in someone with a history of *delays* in speech and language development (see Table 1.3). Currently, there is much debate regarding the validity of this criterion. However, *impairments* in language and nonverbal communication are present, including poorly modulated prosody (intonation, volume, and rate); impoverished or exaggerated nonverbal communication (e.g., gestures and facial expressions); a formal, pedantic, and long-winded linguistic style; and the use of erudite phrases and terminology that are developmentally uncharacteristic and inappropriate for the particular social circumstances. Discussions often are one sided, incessant, circumstantial, and tangential (largely due to a lack of preparation of the listener for topic changes and personal associations).

Another key feature of AS is the presence of intense, preoccupying interests that generally are unusual in nature and highly restricted and narrow in scope and breadth. An impressive store of factual knowledge is accrued on relatively esoteric topics; however, this knowledge is rarely utilized for functional, socially meaningful purposes. Rather, factual knowledge is pursued for its own intrinsic value to the AS individual. In addition, children and adults with AS tend to be physically awkward, uncoordinated, and poor

in judging visual-spatial perspective (often failing to maintain comfortable interpersonal space during social interactions).

With regard to neuropsychological functioning, verbal abilities are generally much better developed than are nonverbal abilities (e.g., perceptual-motor, visual-spatial). In some cases, this pattern appears to be indicative of a nonverbal learning disability (Gunter, Ghaziuddin, & Ellis, 2002; Klin et al., 1995; Rourke & Tsatsanis, 2000; Volkmar & Klin, 1998). In a majority of cases impairments are present in executive functions, including working memory, organization, and cognitive-set flexibility (Miller & Ozonoff, 2000; Ozonoff & Griffith, 2000).

A complementary strategy for assessing the validity of AS vis a vis HFA is to examine the pattern of associated symptomatology. In this regard, a recent study investigated emotional and behavioral disturbance (psychopathology) in 4 to 18-year-olds with HFA and AS (Einfeld & Tonge, 1995). The Developmental Behaviour Checklist (DBC), an informant-based instrument completed by parents and teachers, was used to assess psychopathology. The DBC contains the following six subscales: disruptive, self-absorbed, communication disturbance, anxiety, antisocial, and autistic relating. Its psychometric properties are satisfactory (Einfeld & Tonge, 1991, 1995). After controlling for the effects of age and cognitive level, children and adolescents with AS exhibited higher levels of psychopathology than those with HFA, particularly disruptive behavior, anxiety, and problems with social relationships (Tonge, Brereton, Gray, & Einfeld, 1999).

Rett's Disorder

Rett's disorder is one of the two PDD syndromes in that there is a marked deterioration in global functioning. First described by Andreas Rett in 1966, the syndrome that bears his name has been linked to mutations of the MECP2 gene on chromosome Xq28 (Amir et al., 1999; Ellaway & Christdoulou, 1999; Gura, 1999; Van den Veyver & Zoghbi, 2002). The disorder is far more common in females, although an increasing number of males have been identified (aided by recent genetic findings; Moog et al., 2003; Zeev et al., 2002).

Following 6 to 12 months of apparently normal development, a significant developmental regression occurs, affecting a range of developmental domains (see Table 1.4). Although head circumference is normal at birth (with no clear indications of perinatal abnormalities), a deceleration in head growth ensues. In addition, purposeful hand use declines as an apparent motor apraxia develops (affecting both gait and functional hand use). Over the next months, severe to profound mental retardation becomes apparent, as well as marked impairments in speech and language development and in social relatedness and reciprocity. In addition, a distinctive pattern

TABLE 1.4
DSM-IV Diagnostic Criteria for Rett's Disorder

A. All of the following
(1) Apparently normal prenatal and perinatal development
(2) Apparently normal psychomotor development through the first 5 months after birth
(3) Normal head circumference at birth
B. Onset of all of the following after the period of normal development
(1) Deceleration of head growth between ages 5 and 48 months
(2) Loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand wringing or hand washing)
(3) Loss of social engagement early in the course (although often social interaction develops later)
(4) Appearance of poorly coordinated gait or trunk movements
(5) Severely impaired expressive and receptive language development with severe psychomotor retardation

of motor stereotypy develops, namely, midline hand-wringing movements (except among some affected males). In a high percentage of cases unusual breathing patterns (e.g., periods of hyperventilation) and bruxism (tooth grinding) are prepresent. Additional features include the development of seizures and musculoskeletal abnormalities (scoliosis, peripheral muscle wasting, and hypotonia) (group, 1988; Hagberg, 2002; Hagberg, Hanefeld, Percy, & Skjeldal, 2002). These clinical features reach a plateau in late adolescence and early adulthood. Although the prognosis in Rett's disorder is quite poor, some stabilization of functioning often occurs, particularly with regard to social interactions and relatedness. Some clinical investigators have reported a somewhat reduced life expectancy; however, this is not significant as long as rigorous medical care and supervision are provided.

Childhood Disintegrative Disorder

The other regressive form of PDD recognized by *DSM-IV* and *ICD-10* is termed *childhood disintegrative disorder* (CDD) (Volkmar, 1992, 1996; Volkmar & Rutter, 1995) (see Table 1.5). Originally described as disintegrative psychosis (or dementia infantilis) by Heller in the early 1900s, the condition is very rare, perhaps 1/10 as common as autism (Volkmar, Klin, Marans, & Cohen, 1997). It differs from autistic disorder primarily in its distinctive onset and course. Following at least 2 years (typically 3 to 4 years) of what appears to be perfectly normal development, children with CDD experience a dramatic developmental deterioration (either abrupt—days or weeks; or gradual—weeks or months). The loss of skills involves at least two of the following areas: language, social skills, play, motor skills, and toileting. In

TABLE 1.5
DSM-IV Diagnostic Criteria for Childhood Disintegrative Disorder

A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior
B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas
   (1) Expressive or receptive language
   (2) Social skills or adaptive behavior
   (3) Bowel or bladder control
   (4) Play
   (5) Motor skills
C. Abnormalities of functioning in at least two of the following areas
   (1) Qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
   (2) Qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play) and stereotyped and repetitive use of language or idiosyncratic language
   (3) Lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level
   (4) Restricted repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypies and mannerisms
D. The disturbance is not better accounted for by another specific PDD or by schizophrenia

addition, atypical patterns of development arise within at least two developmental domains involved in autism (e.g., social reciprocity, pragmatic communication, behavioral atypicality). In some cases, this dramatic deterioration is heralded by an identified neurobiological insult; however, in the significant majority of cases the etiology remains unknown. It is important to note that the developmental regression is significant and follows a normal period of development, including age-appropriate phrase and sentence speech, imaginative and early interactive play, and social interest and participation. The regression is not limited to the loss of several words or short phrases and decreased interest in social interaction, as often occurs between 18 and 24 months of age among children diagnosed with autism.

Once established, the clinical syndrome of CDD is consistent with that of an ASD (in terms of social and communicative functioning). In a comparison between cases of autistic disorder (AD) and CDD ascertained during the *DSM-IV* field trials, significant differences were found (Volkmar & Rutter, 1995). The CDD cases had a significantly older age of onset (38 months versus 12½ months for the AD cases) and were more likely to be mute, severely cognitively impaired, and living in residential placements. In general, the prognosis for those with CDD is less optimistic than for those with AD (Volkmar et al., 1997). Approximately 75% of the children experience

TABLE 1.6
DSM-IV Diagnostic Criteria for Pervasive Developmental Disorder Not Otherwise Specified

This category should be used where there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment either in verbal and nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities; but criteria are not met for a specific PDD, schizophrenia, schizotypal disorder, or avoidant personality disorder.

a significant developmental and behavioral deterioration, following which a functional plateau is reached. In a relatively small percentage of cases, language and adaptive skills improve; however, a significant recovery is uncommon. Unless a progressive, degenerative neurobiological condition is responsible for the regression, further deterioration does not typically occur.

Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS)

The diagnostic category of PDDNOS is very complex, largely undefined, and highly variable (Towbin, 1997; Volkmar et al., 1994). It is included as a subtype within the *DSM* and *ICD* diagnostic categories of PDDs for several reasons (see Table 1.6). First, in keeping with all other diagnostic categories, a NOS subtype was added to capture cases that embody a symptom profile (and presumed pathogenesis) that is consistent with the general diagnostic concept of the category, yet for a variety of reasons do not meet full algorithm-defined criteria for one of the recognized and reliably diagnosed subtypes. The algorithms were determined by setting cutoff scores (for the total category and for symptom domains), such that the most acceptable balance was achieved among key psychometric variables, including specificity, sensitivity, positive predictive value, and negative predictive value. Second, the PDDNOS classification is meant to include cases in which there is a strong suspicion that the general condition is present, yet because of insufficient information (e.g., developmental and family history, neuropsychological test scores, and age of onset and developmental trajectory), diagnostic confirmation or linkage with a more specific subtype is not possible. Third, some professionals use the category to include cases in which the social–communicative impairment is less severe than expected for someone with the prototypical condition (in this case, AD). Because no specific guidelines are provided, this becomes a subjective judgment. Fourth, cases are included that meet criteria for AS, except for a history of modest delays in language development or mild impairments in cognitive functioning. Fifth, some clinicians and investigators include

"unofficial" clinical diagnostic entities within the PDDNOS category on the basis of shared clinical features. These conditions include atypical development, atypical autism, multiplex developmental disorder, semantic–pragmatic disorder, and schizoid or schizotypal disorder.

The only specified criterion for this category involves the presence of a disorder with similarities to autism, in which there are impairments in social relatedness and in some aspects of communicative or behavioral development and functioning. Given the largely undefined nature of this diagnostic category and the many different (but acceptable) ways in which this category is used, there is a lack of clinical consistency and homogeneity within and across the subject populations reported in research studies. This seriously hampers attempts to compare and contrast findings across studies and to draw valid and reliable conclusions from analyses of clinical data. An additional complication that was present in the original *DSM-IV* criteria was rectified in 2000 (Volkmar, Shaffer, & First, 2000). In order to maintain consistency across all diagnostic categories, the 1994 release of the *DSM-IV* stipulated that satisfaction of the criteria for any one of the three clinical domains of PDD could qualify for a diagnosis. This allowed for the diagnosis of PDD in the absence of the essential underlying clinical feature, namely, a distinctive impairment in social interaction and reciprocity. In view of the seriousness of this oversight, an amendment was added to the criteria that required the presence of autistic social dysfunction (Volkmar et al., 2000).

Given the lack of diagnostic specificity inherent in the PDDNOS category, and the resultant subject heterogeneity, it is not surprising that relatively poor interrater reliability has been reported for the distinction between autism and the other PDDs, including PDDNOS (Mahoney et al., 1998; Volkmar et al., 1994). This stands in contrast with high reliability figures for the distinction between autism or PDD and non-PDD conditions (Mahoney et al.; Volkmar et al.).

Despite these difficulties, several studies have reported clinical features that are characteristic of PDDNOS, as well as symptoms that appear to distinguish PDDNOS from autism. In a recent study of emotional role taking, children diagnosed with PDDNOS performed similarly to typically developing children in their ability to infer other people's emotions on structured role-taking tasks (Serra, Minderaa, van Geert, & Jackson, 1999). However, on a task involving free person descriptions, "the children with PDDNOS used fewer inner, psychological characteristics to describe peers" (Serra et al., 1999). In comparison with autism, PDDNOS is associated with less impaired cognitive, communicative, and social functioning (Cohen, Paul, & Volkmar, 1986). In addition, interests are less restricted, play is more imaginative, nonverbal communication is better developed, and the disorder is recognized at an older age (Buitelaar, Van der Gaag, Klin, & Volkmar, 1999).

Most experienced clinicians and clinical investigators would agree that the PDD diagnostic category should be reserved for persons who meet clinical criteria for a true autism-related condition (i.e., the presence of qualitative impairments in social reciprocity and pragmatic communication), yet whose developmental profile does not satisfy criteria for a specific PDD subtype (for the reasons discussed previously). However, with the recent broadening of the diagnostic concept of autism and the complexities of integrating dimensional and categorical approaches to diagnosis that are inherent in the PDD concept (i.e., adoption of the term *autism spectrum*), some professionals have become overly inclusive with the PDD designation. There is an increasing tendency to diagnose some children and adults with autism or AS or PDD, whose clinical profile is more accurately conceptualized as social phobia and secondary withdrawal, a nonverbal learning disability complicated by secondary depression, and a developmental language disorder in the presence of an attention deficit hyperactivity disorder (ADHD). Because optimal educational and treatment programming and ultimate prognosis differ significantly for those with ASD versus those with these other conditions, it is incumbent on professionals to strive for an accurate diagnosis. Although there does appear to be an autistic spectrum within the PDD diagnostic category, it cannot be assumed that this spectrum is contiguous with the social distribution for the general population. It appears more likely that a categorical distinction exists between autism or PDD and the upper end of the normal distribution for self-sufficiency, individualism, and the pursuit of personal interests. Given our current state of knowledge, there appears to be a premature blurring of these boundaries.

Studies are being conducted to validate PDDNOS and to distinguish it from non-PDD conditions that share some clinical features. For example, PDDNOS has been distinguished from developmental language disorders by the presence of social impairments, such as deficits in *theory of mind* (*ToM*—the ability to infer mental states in others) as assessed by false belief tasks (Sicotte & Stemberger, 1999). This holds true when gender and verbal mental age are held constant.

Among the clinical entities that are often categorized within the PDD rubric, schizoid disorder, multiplex developmental disorder, and semantic–pragmatic disorder warrant some discussion. The concept of schizoid personality disorder bears similarities to PDDNOS and AS, particularly with regard to symptoms of social isolation or withdrawal, a lack of social adroitness, a preference to engage in solitary activities, and restricted interests (Chick, Waterhouse, & Wolff, 1979; Wolff, 2000a; Wolff & Barlow, 1979; Wolff & Chick, 1980). However, social understanding is often better developed and interpersonal interactions and relationships are often less impaired than they are in autism, at least in structured situations (Volkmar et al., 1999; Wolff, 2000b).

PDD-Related Disorders

Multiplex Developmental Disorder

Multiple complex developmental disorder (or *multiplex developmental disorder* [MCDD]) is a diagnostic concept closely related to PDDNOS (Cohen, Towbin, Mayes, & Volkmar, 1994; Demb & Noskin, 2001; Klin, Mayes, Volkmar, & Cohen, 1995; Paul, Cohen, Klin, & Volkmar, 1999; Scheeringa, 2001; Zalsman & Cohen, 1998). MCDD has been defined as a developmental disorder in which deficits are present in affective regulation and modulation, social relatedness and sensitivity, attachment, and thought stability (Cohen et al., 1986, 1994; Zalsman & Cohen, 1998). Specific criteria have been developed and exhibit good interrater reliability (Towbin, Dykens, Pearson, & Cohen, 1993). In a recent study of 15 children diagnosed as manifesting MCDD (applying the criteria of Towbin et al., 1993), the following symptoms were most common: disturbed attachments (82%), idiosyncratic anxiety reactions (64%), episodes of behavioral disorganization (64%), and wide emotional variability (54%) (Demb & Noskin, 2001). The data also suggested the presence of two distinct behavioral clusters, with one similar to so-called borderline syndromes and the other similar to PDD. The social impairment present in MCDD is less severe, and interest in developing and maintaining relationships is greater than that in autism, and perhaps in the majority of children diagnosed with PDDNOS.

Semantic–Pragmatic Disorder (SPD) or Pragmatic Language Impairment (PLI)

Semantic-pragmatic disorder (SPD; Bishop & Rosenbloom, 1987), more recently termed *pragmatic language impairment* (PLI; Bishop & Norbury, 2002), has received increasing attention, particularly regarding its relationship to ASD. SPD or PLI includes the following clinical features: a verbose linguistic style; difficulties understanding and constructing clear, meaningful, and sequentially related conversations; as well as atypical language forms and content, such as tangential, stereotyped, or socially inappropriate phrases and comments. Some investigators report findings supporting the viewpoint that SPD or PLI may be a subtype of HFA (Shields, Varley, Broks, & Simpson, 1996a, 1996b), because subjects with PLI perform more similarly to those with autism and to those with specific language impairment (SLI) on measures of social cognition and neuropsychological functioning. In contrast, other investigators (Bishop, 1998, 2000; Bishop & Adams, 1989) have asserted that PLI falls on a continuum between SLI and autism. They have found that only some children with PLI meet full or partial diagnostic criteria for ASD (Bishop, 1998). In a recent study, the Children's Communication Checklist (CCC) was used for assessing language structure (speech

and syntax), pragmatics, and nonlinguistic characteristics of autism. A subgroup of children with "pure" SPD did not differ from children with SLI in the quality of their social relationships or in the nature of their preferred interests (Bishop, 1998). With the obvious exception of impairments in language pragmatics and semantics, children in this pure SPD group exhibited none of the social or behavioral features of autism.

In a follow-up study (Bishop & Norbury, 2002), the relationship between PLI and autism or PDD was investigated in greater detail among children 6 to 9 years of age. The following hypotheses were studied: PLI is a subtype of autistic disorder, PLI is a subtype of autism or a related PDD, or PLI and autism or PDD are distinct conditions (with the possibility of different underlying semantic and pragmatic impairments); however, some children may manifest both conditions. Subjects received a general speech and language assessment and were separated into SLI and PLI groups on the basis of results from the CCC. Additional comparison groups included subjects with autistic disorder and those with typical development. Diagnostic instruments for autism or PDD were administered, including the Autism Screening Questionnaire (ASQ), the Autism Diagnostic Interview—Revised (Lord et al., 1997; Lord, Rutter, & Le Couteur, 1994; Lord, Storoschuk, Rutter, & Pickles, 1993) and the Autism Diagnostic Observation Schedule–Generic (Lord et al., 2000). Within the total PLI group, 16% met criteria for AD, and among 13 children with PLI in the first of two study phases, an additional 15% met criteria for PDDNOS. However, a subset of children with pragmatic impairments were not diagnosed as manifesting ASD, presenting as sociable, communicative, normal in their use of nonverbal communication, and free from other features of autism.

Shields (1991) found that adults who had sustained right hemispheric lesions exhibited similar speech and language abnormalities as children diagnosed with semantic–pragmatic language disorder, including fluent and complex language; atypical prosody; poor comprehension of metaphor, humor, inferential meaning, and paralinguistic features; and limited sensitivity regarding the appropriate choice of language for varying social contexts (Shields). Similar findings were reported for a group of children with high-level autism (in contrast with children manifesting phonologic–syntactic language impairments and those with normal development) (Shields et al., 1996a). The authors hypothesized that the impairments in communication and cognition present among those with SPD and autism may reflect underlying right hemispheric dysfunction. In another study by the same investigators (Shields et al., 1996b), children with SPD exhibited similar deficits on tests of social cognition (theory of mind, social comprehension, and detection of eye direction) as children with high-level autism. The performance of both of these groups was inferior to that of comparison groups of children with phonologic–syntactic language impairment and normal development.

The authors conjectured that semantic–pragmatic language disorder may lie on the autistic spectrum (Shields et al., 1996b).

Associated and Co-morbid Conditions

Frequently, the PDDs are accompanied by associated symptom clusters. Whether these should be considered part of the syndrome of autism itself or designated as independent, co-morbid disorders remains controversial. Approximately 70% to 75% of individuals with autistic disorder also have mental retardation (appropriately considered a co-morbid) (Volkmar et al., 1999; Volkmar & Klin, 1999). In addition, a significant number of those with PDD engage in stereotyped and self-stimulatory mannerisms and behaviors. However, this symptom cluster should be considered part of the autism syndrome and not a separate stereotyped movement disorder. In a small percentage of autism cases, motor and phonic tics develop, suggesting co-morbidity with Tourette's syndrome. However, it is important to distinguish tics from motor stereotypy. In addition, many individuals with autism exhibit signs and symptoms suggestive of an ADHD (e.g., overactivity, selective attentional weaknesses, distractibility, and impulsivity). However, these symptoms may reflect underlying neuropsychological and behavioral features of autism rather than the presence of a co-morbid ADHD. In many cases, inattention and distractibility are secondary to confusion, limited motivation, and the relatively low reinforcement value of attention and praise, rather than to a separate neurophysiological abnormality. However, in some cases, particularly those with AS or PDDNOS, a co-morbid ADHD diagnosis may be justified.

Symptoms of anxiety occur frequently among those with pervasive developmental disorders (often becoming increasingly prominent as individuals with AS and PDDNOS mature). A broad range of anxiety symptoms can arise, including panic-like episodes and compulsive-like behavioral patterns. Highly ritualistic ordering and rearranging behavior, marked intolerance for minor changes in the environment and daily routines, a preoccupation with order and symmetry, and in some cases, distressingly intense compulsive rituals can occur. Although the continuity of these symptoms with obsessive–compulsive disorder (OCD) remains uncertain, anxiety and distress often are clearly present. For individuals with PDD who experience highly distressing, ego-dystonic symptoms, a co-morbid diagnosis of OCD may be appropriate. However, for others, the repetitive thoughts and behaviors appear to represent pleasurable preoccupations (and, hence, may bear a closer relationship to impulse control disorders that to OCD).

Among those with AS and HFA, depression can sometimes occur in adolescence and young adulthood, often in response to social failure and marginalization. There have been reports of mood disorders, such as bipolar

disorder, in persons with autism and family members (DeLong & Dwyer, 1988); however, a definitive association has not been established.

In approximately 20% of autism cases, a seizure disorder develops (not uncommonly during adolescence) (Tuchman, 2000; Volkmar, 2000). The rare condition, acquired developmental aphasia with epilepsy (Landau-Kleffner syndrome), should be included in the differential diagnosis of PDD for cases with a later onset, significant regression in speech and language functioning, and relative preservation of social interest or relatedness and nonverbal communication. A distinctive EEG pattern is often present, although rigorous electroencephalographic efforts are sometimes necessary to document this.

Differential Diagnosis of Non-PDD Disorders

There are a number of clinical similarities between ASD and the prodromal and nonpsychotic phases of early-onset schizophrenia (EOS), including social discomfort and isolation, reduced eye contact, social awkwardness, unusual language patterns (e.g., indirect, and metaphorical), perseverative behaviors, restricted interests, misinterpretation of subtle social cues, overly concrete thought processing, and so-called negative symptoms (e.g., blunted or inappropriate affect, reticence, reduced motivation, and apathy). Another similarity is the presumed developmental nature of both conditions. Recent findings suggest that schizophrenia (similar to autism) may be a neurodevelopmental disorder, with origins early in life (Hakak et al., 2001). In fact, early conceptions of autism included a continuity with schizophrenia and related psychotic disorders (Volkmar et al., 1999; Volkmar & Klin, 1999). During the past several decades, autism and schizophrenia have been shown to be distinct disorders genetically, developmentally, and symptomatically. Despite some apparent behavioral similarities, EOS is associated with better social reciprocity and understanding and the capacity to maintain interpersonal relationships that include mutuality. Despite several case reports suggesting that children with autism may be at increased risk for the development of co-morbid schizophrenia, systematic studies have negated this suggestion (Volkmar & Cohen, 1991).

Although the initial social impairments exhibited by children with reactive attachment disorders (RAD) may resemble those present in ASD, marked improvement occurs once adequate care and nurturance are provided (Richters & Volkmar, 1994; Volkmar et al., 1999). The quality of social interactions and the ability to infer mental states (thoughts, feelings, attitudes, and intentions) in others are better developed among those with RAD; however, lower levels of social functioning are present than observed in other clinical disorders (Boris, Zeanah, Larrieu, Scheeringa, & Heller,

1998). In addition, there are suggestions that the a reliable diagnosis of attachment disorder can be made in the absence of unequivocal evidence of early "pathogenic" care (Boris et al.).

STANDARDIZED DIAGNOSTIC INSTRUMENTS

Preschool Measures

In view of the complexity of differential diagnosis among preschoolers, clinical investigators have been working toward the development of screening tools capable of identifying young children at risk for the development of ASDs (see Table 1.7). Among the most promising tools are CHAT; Baird et al., 2000; Baron-Cohen, Cox, Baird, Sweettenham, & Nighingale, 1996; Baron-Cohen et al., 1996, 2000), the Modified-Checklist for Autism in Toddlers (M-CHAT; Charman et al., 2001; Robins, Fein, Barton, & Green, 2001), and the Screening Test for Autism in Two-Year-Olds (STAT; Stone, Coonrod, & Ousley, 2000). Preliminary studies of these instruments indicate good psychometric properties (e.g., discriminent validity and interrater and intratest item reliability, sensitivity, specificity, positive predictive value, and negative predictive value). Increasing numbers of studies are being designed to assess the usefulness of these measures both as screening instruments within the general preschool population and as diagnostic instruments among children suspected of manifesting an ASD. However, it is important to keep in mind that these three instruments were developed with

TABLE 1.7
Preschool Screening Checklists

Instrument	*Type of Screening*	*Informant*	*Characteristics*
CHAT	First-degree level	PCP[a]	14-Item checklist developed to screen for early social-communicative behaviors, particularly joint attention and imaginative play
M-CHAT	First- & second-degree levels	Parent	23-Item scale—particularly salient: pointing to express interest, responsiveness to name, interest in peers, showing behavior, response to joint attention, social imitation
STAT	Second-degree level	Specialist	12-Item checklist derived from measures of play, imitation, & social communication; administered in a playlike interaction

[a]PCP, Primary care professional.

different objectives. The CHAT was designed solely as a general population-screening instrument for use by primary care practitioners in their routine well-child-care roles (particularly for toddlers 18 months of age). It is intended to identify young children who may be at risk for ASD and who should be referred for a more comprehensive assessment (or series of assessments that increase in specificity, as clinically indicated). The M-CHAT was conceived to improve the sensitivity of the CHAT by adding items to accommodate a slightly older population (18 to 24 months) and to adapt it for use in the United States and other countries in which home health care practitioners do not routinely screen the general childhood population. Although ostensibly designed as a population-screening instrument, the M-CHAT also has been used by its developers as a second-level screen among preschool children (18 to 30 months of age) already identified at risk for a developmental disorder by early intervention professionals. In contrast, the STAT was developed as a second-level screen for use as a source of diagnostic information in the assessment process.

The CHAT is a brief, 14-item checklist developed to screen for early social–communicative behaviors, particularly joint attention and imaginative play, within the general childhood population. Nine items are completed during a brief parental interview by the primary care physician, and five items are completed by a home health visitor (the CHAT was developed for use in Britain). The items found to be the most strongly associated with autism included protodeclarative pointing (pointing to share an observation or interest), gaze monitoring, and imaginative play. The CHAT has been studied in large populations as a screening instrument to detect early signs of atypical development that may signify the presence of ASD (Baird et al., 2000; Baron-Cohen et al., 1996). In a longitudinal study, 16,235 toddlers 18 months of age were screened by their primary care clinicians (Baird et al., 2000). Cases were reevaluated when the children were 3, 5, and 7 years of age in order to assess the sensitivity, specificity, and positive predictive value of the CHAT in diagnosing childhood autism. At 18 months, 19 of the toddlers were identified by the CHAT as being at risk for autism. At follow-up, 50 of the children met criteria for autism when all sources of information were considered. On this basis, the CHAT exhibited a sensitivity of 38% and a specificity of 98%. When maximized by repeat screening at 1 month, the positive predictive value was 75% but the sensitivity declined to 20%, and the specificity rose close to 100%. In addition to autism, the screen also was successful in identifying cases of PDD and other developmental disorders (e.g., language). The authors concluded that the CHAT can be used to identify cases of autism and PDD at 18 months of age. Given its relatively low sensitivity, it should not be considered an adequate screen to rule out potential cases of autism; however, in view of its high specificity, it is quite useful in distinguishing autism from other developmental conditions. It is

of interest that Scambler, Rogers, and Wehner (2001) achieved a sensitivity of 85% and a specificity of close to 100% by slightly altering the original CHAT criteria.

The M-CHAT is a 23-item scale that is scored dichotomously (with yes or no responses; Robins et al., 2001). It was adapted and expanded from the CHAT to serve as a screening instrument within the health care environment of the United States. It includes the nine parent report items from the CHAT, in addition to items derived from previous research and clinical experience that involve developmental domains affected in autism, including language, arousal modulation, sensory responsiveness, theory of mind, motor functions, and social and emotional development, among others. Following a preliminary analysis the original 30 items were reduced to 22 and an additional item was added (social referencing deficits). Six items were found to be particularly salient on discriminant function analysis, including pointing to express interest, responsiveness to his or her name, interest in other children, showing behavior, response to joint attention, and social imitation. Internal reliability was judged to be adequate, with Cronbach's alpha coefficients of 0.85 and 0.83 for the entire checklist and the critical items, respectively. The sensitivity, specificity, positive predictive power (PPP), and negative predictive power (NPP) for the 23-item scale and the six best items, were as follows: sensitivity, 0.97 and 0.95, respectively; specificity, 0.99 and 0.98, respectively; PPP, 0.68 and 0.79, respectively; and NPP, 0.99 and 0.99, respectively. The population for which psychometric data were collected included eleven hundred twenty-two, 18- to 24-month-olds screened by primary care physicians during well-child-care visits and one hundred seventy-one, 18- to 30-month-olds screened through early intervention service providers. Therefore, the sample included both nonreferred and "high-risk" populations and constitutes a combined first- and second-stage screen.

STAT is a 12-item, clinician-scored interactive, second-stage screening instrument for preschool children between 24 and 35 months of age (Stone, Coonrod, & Ousley, 2000). It was developed to differentiate children with ASD from those with other developmental disorders. It is administered within the context of a playlike interaction. The items of the STAT were derived from measures of play, imitation, and social communication. In a validation sample of 32 preschool children, the sensitivity of the instrument was 0.83 and the specificity was 0.86.

Informant-Based Measures

Over the years, a number of informant-based questionnaires and checklists have been developed in order to assist in the diagnosis of autism and related

TABLE 1.8
Informant-Based Checklists

Instrument	*Informant*	*Characteristics*
ABC (Krug et al., 1980)	Teacher, parent	57-Item questionnaire for autism; five subscales: sensory, relating, body or object use, language, and social or self-help; fair to good accuracy discriminating autistic from nonautistic developmentally impaired children
ASQ (Berument et al., 1999)	Parent	40-Item checklist derived from the ADI-R;[a] 2 versions: <6 yrs & ≥ 6 yrs; quite accurate in differentiating PDD and autism from non-PDD conditions, it was decidedly less effective in differentiating autism from other subtypes of PDD
DBC-ASA (Brereton et al., 2002)	Teacher, parent	29-Item subscale of the DBC (Einfeld & Tonge, 1991, 1995); good discriminant validity across a wide range of IQ and age
ASSQ (Ehlers et al., 1999)	Teacher, parent	27-Item checklist successful in distinguishing ASD from DBD.[b] Good test–retest and interrater reliabilities & agreement between parents & teachers
AQ (Baron-Cohen et al., 2001)	Self-report	50 Questions for adults with HFA or AS; 5 categories: social skill, attention switching, attention to detail, communication, and imagination; sensitivity, test–retest reliability, & interrater reliability of the AQ are good

[a]ADI-R, Autism Diagnostic Interview—Revised.
[b]DBD, disruptive behavior disorders.

PDDs (see Table 1.8). The earlier instruments tended to focus on behavioral symptoms common among those with classic autistic disorders, such as the Rimland E-2 Scale (Deckner, Soraci, Deckner, & Blanton, 1982) and the Autism Behavior Checklist (ABC; Krug, Arick, & Almond, 1980). More recently developed instruments have focused on symptomatology common among those with HFA, AS, and PDDNOS (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001).

The ABC (Krug et al., 1980) is a 57-item screening questionnaire for autism, designed for completion by teachers (with parental assistance). The developers of the ABC grouped the items into five subscales: sensory, relating, body or object use, language, and social or self-help. Although responses are dichotomous, the items are weighted (in a manner determined by prior statistical analyses of the scale). Based on summary scores, the presence of autism is determined to be unlikely, questionable, or probable. Recent reanalyses of the psychometric properties of the scale have identified a factor structure different from that originally proposed. In one case, a 3-factor

model was suggested (Wadden, Bryson, & Rodger, 1991), and in another, a (different) 5-factor model was suggested (Miranda-Linne & Melin, 2002). Investigators have reported fair to good accuracy discriminating autistic from nonautistic developmentally impaired children (Volkmar et al., 1988; Wadden, Bryson, & Rodger, 1991).

The Autism Screening Questionnaire (ASQ) is a 40-item parent checklist that was derived from the clinician-based semistructured interview, the Autism Diagnostic Interview-R (ADI-R; Berument, Rutter, Lord, Pickles, & Bailey, 1999). The objective was to devise a valid and reliable screening instrument that included items from three areas of functioning known to be impaired in ASD, namely, reciprocal social interaction, language and communication, and repetitive and stereotyped patterns of behavior. The items were modified from the ADI-R in order to make them more understandable to caregivers. The ASQ has two versions: one for children under 6 years of age and one for those 6 and over. In a study of 200 subjects (160 with PDD and 40 with non-PDD diagnoses), 33 of 39 scored items succeeded in statistically differentiating the populations. Correlations between the ASQ and the ADI were highly significant for all three major symptom domains.

Discriminative validity also has been calculated (Berument et al., 1999). The following scores have been reported: PDD versus non-PDD, 0.88; autism versus mental retardation, 0.93; and autism versus other PDDs, 0.73. These scores were very similar to those derived from the ADI. With a cut-off score of 15 (the maximum score is 39), the ASQ exhibited the following psychometric qualities for differentiating PDD from non-PDD conditions: sensitivity, 0.85; specificity, 0.75; positive predictive value, 0.93; and negative predictive value, 0.55. Discriminating autistic disorder proper from other diagnoses resulted in improved discriminatory values, including a sensitivity of 0.96 and a specificity of 0.67. These reported properties of the ASQ may be overestimated, because a majority of the participating families had been interviewed with the ADI-R sometime in the past. Although the ASQ was quite accurate in differentiating PDD and autism from non-PDD conditions, it was decidedly less effective in differentiating autism from other subtypes of PDD. In this regard, it is not dissimilar to other screening questionnaires. The finer points of differential diagnosis are better addressed by more comprehensive assessments, including standardized investigator–clinician diagnostic interviews.

Recently, a 29-item subscale of the Developmental Behaviour Checklist was developed, termed the *Autism Screening Algorithm* (DBC-ASA). The DBC-ASA was piloted in a sample of 180 children with *DSM-IV*-diagnosed autism and 180 controls matched for age, gender, and IQ range (Brereton, Tonge, Mackinnon, & Einfeld, 2002). The DBC-ASA was found to have good discriminant validity across a wide range of IQ (normal to severe mental retardation) and of age (4–18 years). The DBC is the parent and teacher questionnaire from which the DBC-ASA was abstracted. The DBC was developed

to assess signs of affective and behavioral problems in children and adolescents with a range of developmental disabilities (Einfeld & Tonge, 1995). It contains 96 items and is patterned after a questionnaire commonly used within the general population, (CBC). It includes a three-level rating format for each item. The DBC contains six subscales: disruptive, self-absorbed, communication disturbance, anxiety, antisocial, and autistic relating. Its psychometric features are satisfactory, including internal consistency and interobserver agreement (Einfeld & Tonge, 1991, 1995; Tonge et al., 1996).

The Autism Spectrum Screening Questionnaire (ASSQ) is another recently developed screening instrument for HFA or AS (Ehlers, Gillberg, & Wing, 1999). It is a 27-item checklist designed for completion by parents and teachers of children and adolescents suspected of manifesting an ASD and who have IQs at or above the level of mild mental retardation. A 3-point rating scale results in a total score range between 0 and 54. The study population included the following subject groups: ASDs, disruptive behavior disorders (DBD), learning disorders, as well as an AS validation sample. The ASSQ was successful in distinguishing subjects with ASD from those with DBD. Good test–retest and interrater reliabilities were reported, as well as good agreement between parent and teacher ratings. Cut-off scores of 19 for parents and 21 for teachers resulted in true-positive and false-positive rates of 62% and 10% and 70% and 9%, respectively.

Self-Report Measure

A new screening questionnaire, the Autism-Spectrum Quotient (AQ), has been developed for use by adults of average intelligence who are suspected of having traits that fall along the autistic continuum (Baron-Cohen et al., 2001). This self-report measure consists of 50 questions (piloted among adults with HFA, AS, and age-matched controls) that are grouped into five categories, including social skill, attention switching, attention to detail, communication, and imagination. Responses indicating atypicality receive 1 point, resulting in a sum scoring range between 0 and 50. A cut-off score of 32+ resulted in an 80% true-positive identification rate among HFA or AS subjects and a 2% false-positive identification rate among controls (a random community sample and a Cambridge University student sample). The mean AQ total score of adults with AS or HFA was significantly higher than that of the community controls. Within the AS or HFA group, male and female scores did not differ significantly. Test–retest and interrater reliability of the AQ was good. The developers concluded that the AQ appears to be a valuable screening instrument for estimating where on the continuum from autism to normality adults with average cognitive ability lie.

TABLE 1.9
Investigator- and Clinician-Based Instruments

CARS (Schopler et al., 1980)	15 Scales: Relating to People; Imitation; Emotional Response; Body Use; Object Use; Adaptation to Change; Visual Response; Listening Response; Taste, Smell, and Touch Response and Use; Fear or Nervousness; Verbal Communication; Nonverbal Communication; Activity Level; Level and Consistency of Intellectual Response; and General Impressions; distinguished the subject groups (autism, PDDNOS, non-PDD controls
ADI-R (Lord et al., 1994)	Semistructured diagnostic interview; good interrater reliability and high internal consistency; distinguishes autistic from nonautistic, mentally handicapped, and language-impaired children
ADOS-G (Lord et al., 2000)	A series of "presses" for social & communicative interaction through tasks, play activities, conversational probes; ratings made regarding social, communicative, & behavioral development; excellent interrater and test–retest reliability, internal consistency, sensitivity, & specificity; *DSM-IV- and ICD-10*-diagnostic algorithms; excellent differentiation of autism or PDD from non-PDD, moderate differentiation of autism from PDDNOS
DISCO (Leekam et al., 2002)	For gathering developmental and clinical information relevant to the *broader autism spectrum*; interrater reliability & diagnostic validity are good, particularly for the broader autistic spectrum; not developed in concert with *DSM* or *ICD*

Investigator- and Clinician-Based Instruments

In an effort to standardize the process of diagnosis, particularly for research purposes, clinical investigators have developed diagnostic rating instruments and semistructured diagnostic interviews (see Table 1.9). Clinician-based rating scales were the first to be developed, including the Behavioral Rating Instrument for Autistic and Other Atypical Children (BRIAAC) (Ruttenberg, Dratman, Fraknoi, & Wenar, 1966; Ruttenberg, Wolf-Schein, & Wenar, 1991) and the Childhood Autism Rating Scale (CARS) (Schopler, Reichler, DeVellis, & Daly, 1980).

The CARS is a commonly used clinician-based rating instrument that is completed following a period of observation (typically a clinical evaluation). The CARS consists of 15 scales, labeled: Relating to People; Imitation; Emotional Response; Body Use; Object Use; Adaptation to Change; Visual Response; Listening Response; Taste, smell, and Touch Response and Use; Fear or Nervousness; Verbal Communication; Nonverbal communication; Activity Level; Level and Consistency of Intellectual Response; and General Impressions. The rating of each scale is based on a 7-level ordinal structure (accompanied by anchor-point descriptions). Ratings are made from 1 to 4

in half-point increments. The total sum score range (15 to 60) has been divided into three diagnostic categories (based on previous studies), namely, Nonautistic, Mildly–Moderately Autistic, and Severely Autistic. Final scoring is based on where along this 45-point continuum the individual's total sum score falls.

Two factor analytic studies of the CARS have been conducted. In the first, three factors were identified with moderate to good internal consistency, termed *Social Impairment* (SI), *Negative Emotionality* (NE), and *Distorted Sensory Response* (DSR) (DiLalla & Rogers, 1994). Scores on the SI factor distinguished subjects with autism from those with PDDNOS and non-PDD developmental impairments with 78% accuracy. SI scores improved over time equally across the three subject groups. NE scores were the most responsive, whereas DSR scores were the least responsive to treatment interventions. The second study involved children and adolescents with either autism or PDDNOS (Stella, Mundy, & Tuchman, 1999). Five factors were identified that accounted for 64% of the variance in total CARS scores. The factors were labeled as follows: Social Communication, Emotional Reactivity, Social Orienting, Cognitive and Behavioral Consistency, and Odd Sensory Exploration. Factor-based scales developed during the study distinguished the subject groups (autism, PDDNOS, and nonautistic controls). The results supported the presence of a "partially independent" social impairment domain among the PDD subjects (Stella et al., 1999).

The most systematically investigated and widely used diagnostic interview is the Autism Diagnostic Interview—Revised (ADI-R), a semistructured, investigator-based interview for caregivers of children and adults who are suspected of manifesting autism or a related pervasive developmental disorder (Lord et al., 1993, 1994, 1997; Lord, Leventhal, & Cook, 2001). The psychometric properties of the ADI-R have been studied (Lord et al., 2001). Reliability was assessed among preschool children with autism and mental retardation or language impairment, and validity was assessed among children with and without autism. The ADI-R was found to be reliable and valid for diagnosing autism in preschool children, demonstrating good interrater reliability and high internal consistency (Lord et al., 1994). The ADI-R distinguished autistic from nonautistic, mentally handicapped preschool children (matched on mental and chronological age) on all subdomains of *DSM-IV* and *ICD-10* algorithm criteria (except some aspects of stereotypic language). Fifty of 51 children with clinically diagnosed autism were correctly identified by the ADI-R, and only 2 of 30 nonautistic children 18 months of age and older were misdiagnosed (Lord et al., 1993).

In another study, the ADI-R was successful in differentiating children with autism from those with receptive language disorder (Mildenberger, Sitter, Noterdaeme, & Amorosa, 2001). All subjects had nonverbal IQs falling within the normal range. Only one child with autism and one with receptive

language disorder were misclassified by the *ICD-10* algorithm criteria of the ADI-R. The reciprocal social interaction and language and communication domains were superior to the restricted and stereotyped behavioral domain in differentiating the subject groups (especially among school-age children; Mildenberger et al., 2001).

The degree of diagnostic agreement between the ADI-R and the CARS has been investigated among individuals suspected of manifesting autism (Pilowsky, Yirmiya, Shulman, & Dover, 1998). Concordance was reached in 85.7% of cases (highest among the oldest subjects). Participants who fulfilled ADI-R criteria for autism were older and received higher CARS scores than participants who did not. No gender differences were present between the two instruments.

The Autism Diagnostic Observation Schedule—Generic (ADOS-G) is a companion instrument to the ADI-R and is administered to the identified children and adults. The ADOS-G is a valid and reliable semistructured observation and interview protocol designed to provide clinical information relevant for diagnosing autism and related pervasive developmental disorders (Lord et al., 2000b). The ADOS-G was developed in order to improve the accuracy and reliability of diagnoses within the autism spectrum. It consists of a series of "presses" for social and communicative interaction through the presentation of tasks, play activities, and conversational probes. Based on the age, communicative ability, and developmental level of the individual, one of four modules is selected for administration. The following items are included across the four modules: the quality social greetings and request-helping initiatives; choice making; spontaneous, symbolic, and interactive play; social, functional, and symbolic imitation; joint attention and social referencing; responsiveness to name; responsive social smiling; the quality of help-requesting initiatives; anticipation of routines with objects and of social routines; nonverbal communication (through demonstration or mime); identification of social interactions and activities in pictures; appreciation of sequential plots and themes depicted in social stories; creative story telling; understanding of higher order social concepts (e.g., humor, intent, irony, and alternate points of view), general conversational ability; and insight regarding the nature of social topics (e.g., emotions and feelings, relationships—close friendship, family ties, romantic relationships, interpersonal conflict, loneliness, self-conception, future goals, and aspirations). Scoring of the ADOS is based on assessments of the quality of reciprocal social interaction, pragmatic communication and play, as well as on the presence of restricted, stereotyped, and ritualistic behavior.

The psychometric properties of the ADOS-G have been assessed among 223 children and adults with autistic disorder, PDDNOS, and non-PDD disorders (Lord et al., 2000). Highly significant values for the following were found: interrater and test–retest reliability for individual items, interrater

reliability within domains, and internal consistency. Autism and PDDNOS were accurately differentiated from non-PDD conditions; however, differentiation of autism from PDDNOS was less robust. Excellent sensitivity (87%–100%) and specificity (90%–94%) of the *DSM-IV- and ICD-10*-diagnostic algorithms were achieved for autism and PDDNOS relative to non-PDD disorders, with moderate differentiation of autism from PDDNOS (Lord et al., 2000).

Another investigator-based schedule for interviewing parents and caregivers is the Diagnostic Interview for Social and Communication Disorders (DISCO), currently in its ninth edition (Leekam, Libby, Wing, Gould, & Taylor, 2002). The DISCO was developed with the goal of gathering developmental and clinical information relevant to the *broader autism spectrum* and to aid in case formulation and clinical diagnosis. Unlike the ADI-R, the DISCO was not developed in concert with the major schemes of categorical diagnosis (i.e., *DSM* and *ICD*), and is more dimensional than categorical in its approach. Algorithms have been derived for *ICD-10* childhood autism and for the broader autistic spectrum. Measures of interrater reliability and diagnostic validity are good, particularly for the broader autistic spectrum (Leekam et al., 2002).

SUMMARY: DEFINITIONS AND CHARACTERISTICS OF THE SPECTRUM

Autism and related PDDs are early-onset neurobiological conditions that share fundamental impairments in social reciprocity, pragmatic and semantic communication, reactions to environmental stimuli, and the nature of preferred interests and activities. Although there is a broad range of cognitive, linguistic, and adaptive functioning across the autism spectrum, impairments in social understanding, emotion perception, and pragmatic communication are universally present. Currently, there are several PDD (or ASD) subtypes recognized by the principal diagnostic systems, the *DSM-IV*, and the *ICD-10*, namely, autistic disorder, disintegrative disorder, Rett's disorder, Asperger's disorder, and PDDNOS.

Autism and related conditions are disorders of neurodevelopmental connectivity, with suspected structural and functional abnormalities in brain regions that are primarily responsible for social, communicative, and executive functions (e.g., the orbitofrontal cortex and regions of the temporal lobe and related limbic system). There are many different proximal causes of autism, including genetic etiologies (i.e., autism-specific susceptibility genes, more global genetic disorders, such as some causes of tuberous sclerosis and fragile X syndrome).

During the past decade, the reported prevalence of ASD has markedly increased because of earlier and more accurate diagnosis, recognition of a broader spectrum, and increased awareness among primary practitioners, educators, and parents. However, other factors may be operative as well.

Both clinical and basic science research regarding the etiology, pathogenesis, clinical pharmacology, and treatment of autism spectrum disorders has been expanding, particularly with regard to interdisciplinary investigations, international collaboration, and public–private funding. Given this impressive effort, it is likely that major advances in our understanding of these serious neurobiological conditions will be forthcoming during the next decade.

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Chapter 2

Recent Neurobiological Research in Autism

Luke Y. Tsai
University of Michigan Medical Center

INTRODUCTION

Although some people may still believe in the psychogenic hypothesis of autistic disorder (autism), most authorities in the field of autism agree that neurobiological factors are of crucial importance in terms of causes of autism. An important piece of evidence that supports the neurobiological hypothesis is the association of mental retardation with autism: About three out of four individuals with autism also have lower cognitive functioning (i.e., mental retardation), which generally indicates some serious damage or dysfunction of the brain. In addition to the presence of global mental retardation, certain neurological abnormalities have been reported in 30% to 75% of several groups of individuals with autism (reviewed by Tsai, 1999). Furthermore, the majority of the individuals with autism have severe impairment in speech and language development which reflects damage or dysfunction of certain brain structure or of the neurological system. However, despite strong evidence pointing to a neurobiological etiology of autism, the exact cause(s) and nature of the basic defect remain unclear.

It is somewhat disappointing that the road leading to the final answer of "*autism pathogenesis*" is still quite long. There are, however, some exciting and encouraging recent neurobiological studies in the field of autism. This chapter reviews these studies in the hope that the information presented here will help parents and professionals caring for individuals with autism

gain more knowledge of the neurobiological aspect of autism. It should be pointed out that in the present chapter, only those studies published since 1997 are described in detail. The studies published before 1997 were reviewed in the previous edition of this book (Tsai, 1999). The other reason for this decision is that the current psychiatric diagnostic system (Diagnostic and *Statistic Manual of Mental Disorder,* 4th ed. [DSM-IV]) of the American Psychiatric Association was established in 1994 (APA, 1994). Hence, most research reports published since 1997 tend to be based on the current diagnostic concept and system.

STUDIES OF PREVALENCE OF ASSOCIATED MEDICAL CONDITIONS OR DISORDERS

There is general agreement that autistic disorder has an organic basis, but there is less agreement on the frequency with which it is associated with known medical conditions. After a review of the existing literature, Rutter, Bailey, Bolton, and Le Couteur (1994) concluded that the rate of known medical conditions in autism is probably about 10%, and that the rate is higher in autistic disorder associated with profound mental retardation and in cases of atypical autism. Fombonne, du Mazaubrun, Cans, and Grandjean (1997a) concluded from a French epidemiological survey that known medical disorders (excluding epilepsy and sensory impairments) accounted for fewer than 10% of the cases of autism. Gillberg and Coleman (1996) reported a higher rate of 24.4% with known medical conditions, but with a similar trend for higher rates of medical disorders among individuals with both autism and severe mental retardation. Barton and Volkmar (1998) retrospectively reviewed medical records of 211 subjects with autism and found the prevalence of associated medical conditions varied between 10% and 15%, and with less strict definition of medical condition, between 25% and 37%. However, these medical conditions or disorders are not considered to be the causes of autism.

STUDIES OF NEUROLOGICAL ABNORMALITIES

Neurological abnormalities have been reported in 30% to 50% of several series of autistic patients (reviewed by Tsai, 1999). These abnormalities include hypotonia or hypertonia, disturbance of body schema, clumsiness, choreiform movements, pathological reflexes, myoclonic jerking, drooling, abnormal posture and gait, dystonic posturing of hands and fingers, tremor, ankle clonus, emotional facial paralysis, and strabismus. These are all signs of

dysfunction in the basal ganglia, particularly in the neostriatum, and closely related structures of the medial aspects of the frontal lobe or limbic system.

Kanner (1943) reported that 5 out of 11 individuals with "infantile autism" seemed to have "relatively large heads" (i.e., macrocephaly). Recently, several investigators reported that some individuals with autism (from 12% to 46%) had macrocephaly (head circumference > 97th centile) (Davidovitch, Patterson, & Gartside, 1996; Fidler, Bailey, & Smalley, 2000; Lainhart, et al., 1997; Piven et al., 1995; Woodhouse et al., 1996). Fidler et al. also noted that the first-degree relatives of these patients also had a higher rate of macrocephaly when compared against a published normative sample. Aylward, Minshew, Field, Sparks, and Singh (2002) found that brain volumes were significantly larger for children with autism 12 years old or younger as compared to those of normally developing children, but there was no difference in brain volumes between individuals older than age 12 with or without autism. Head circumference was increased in both younger and older groups of subjects with autism, suggesting that those subjects older than age 12 had increased brain volumes as children. However, Courchesne, Muller, and Saitoh (1999) reported that the brain weight was normal in most postmortem cases of autism, and in a few cases microcephaly (i.e., relatively smaller head) had also been observed. Other investigators questioned the specificity of macrocephaly to autism (Ghaziuddin, Zaccagnini, Tsai, & Elardo, 1999).

Based on the analogy to signs and conditions seen in adults with certain forms of brain damage, Damasio and Maurer (1978) proposed that autism results from dysfunction in a system of bilateral central nervous system structures that include the ring of mesolimbic cortex located in the medial frontal and temporal lobes, the neostriatum, and the anterior and medial nuclear groups of the thalamus. They suggested that such dysfunction might involve macroscopic or microscopic cerebral changes consequent to a variety of causes, such as perinatal viral infection, insult to the periventricular watershed area, or genetically determined neurochemical abnormalities. Although this hypothesis is plausible, it needs to be verified.

On the other hand, Haas et al. (1996) noted that the rates of showing abnormal scores on tests that reflect cerebellar and parietal lobe dysfunctions as well as of the neurological abnormalities detected by the magnetic resonance imaging (MRI) were significantly greater in individuals with autism than in healthy controls. This finding suggests a hypoplasia or hyperplasia of the vermis of cerebellar. They concluded that a cerebellar and parietal structural abnormality can lead to abnormalities that can be detected during the clinical neurological examination.

In summary, neurological studies do provide some support for the notion that autism is a neurobiological disorder. However, they tell little about the

causes of the neurological abnormalities and the operating mechanisms that produce autism.

STUDIES OF CONGENITAL, PERINATAL, AND POSTNATAL FACTORS

Results of numerous studies show that many autistic children have organic brain disorders. A wide variety of neurological disorders have been reported: cerebral palsy, congenital rubella, toxoplasmosis, tuberous sclerosis, cytomegalovirus infection, lead encephalopathy, meningitis, encephalitis, severe brain hemorrhage, many types of epilepsy, and others. Many of these neurological or congenital disorders derive from prenatal, perinatal, and neonatal complications. Several investigators report that pre-, peri-, and neonatal complications (reduced optimality) appear with increased frequency in the histories of autistic patients. These include increased maternal age, first- and fourth- or later–born children, bleeding after the first trimester, use of medication, and meconium in amniotic fluid (reviewed by Tsai, 1999). Burd, Severud, Kerbeshian, and Klug (1999) identified five variables (decreased birth weight, low maternal education, later start of prenatal care, having a previous termination of pregnancy, and increasing father's age) were associated with increased risk of autism. Juul-Dam, Townsend, and Courchesne (2001) reported an association of unfavorable events in pregnancy, delivery, and the neonatal phase and autism. Recently, Hultman, Sparen, and Cnattingius (2002) reported the risk of autism was associated with daily smoking in early pregnancy, maternal birth outside Europe and North America, cesarean delivery, being small for gestational age, a 5-minute Apgar score below 7, and congenital malformations. No association was found between autism and head circumference, maternal diabetes, being a twin, or season of birth.

On the other hand, other investigators proposed that pre- and perinatal factors might play less of a role in autism in higher functioning individuals; that the reported association between optimality and autism in autistic probands and their siblings might be the result of failure to control for birth order; that obstetric complications usually appeared to be consequences of genetically influenced abnormal development, rather than of independent etiological factors; that obstetric adversities associated with autism either represented an epiphenomenona of the condition or derived from some shared risk factor(s); and that individuals with autism did not differ from controls in terms of risk factors for autism (maternal age, maternal parity, birth order, and low birth weight; reviewed by Tsai, 1999; and Zwaigenbaum et al., 2002).

In summary, because of the lack of uniformity in applying diagnostic criteria to autism as well as to the selection of obstetric complications, the findings on the association between optimality and autism should be accepted cautiously. Also, the data reviewed here do not indicate a unifying pathological process in autism.

NEUROPATHOLOGICAL STUDIES

One way to study the association between a specific neurobiological disorder and brain pathology is to examine the brains of deceased individuals (i.e., postmortem brain study) by macroscopic, microscopic, and biochemical means. Biochemical study of the postmortem human brain includes measures of the level of various neurotransmitters and their metabolites, as well as receptor populations and activities in various brain areas, to obtain some sense of the state of regional neurotransmission. This later research approach, however, has not been launched by any investigator in the field of autism.

Very few postmortem neuropathological studies have been done in deceased individuals with autism. Investigators have reported findings that include no specific neuropathology; no consistent neuropathology; increased cell-packing density and reduced cell size bilaterally in the hippocampus, subiculum, entorhinal cortex, portions of the amygdala, the anterior cingulate, the mammillary body, and the medial septal region; variable loss of Purkinje cells sometimes accompanied by gliosis; loss of granule cells in the neocerebellum; developmental abnormalities of the brainstem (near-complete absence of the facial nucleus and superior olive along with shortening of the brainstem between the trapezoid body and the inferior olives); and megaloencephalic brains (reviewed by Tsai, 1999).

In summary, because all the studies examined only limited brain structures of a few autistic subjects without use of control subjects, the cause-and-effect meaning and the specificity of these findings are unclear. It is also unclear what factor or factors can cause these abnormalities. However, based on previous human fetus studies, Bauman and Kemper (1994) believe that the cerebellar cortical abnormalities have their onset prior to birth, perhaps before 30 weeks of gestation. Because the limbic system is related to cognition, memory, emotion, and behavior, and the cerebellum seems to be involved in some aspects of learning, the findings of Bauman and Kemper provide some exciting information on the possibility of brain lesions for the development of autism and also some directions (i.e., posterior cerebral fossa and limbic structures) for in vivo neuroanatomical imaging studies of autism.

NEUROIMAGING STUDIES

Because the availability of brains of deceased individuals with autism for direct brain study is quite limited, neuroimaging techniques have been applied to examine the association between clinical manifestations of autism and various brain structures and functions. Contemporary brain-imaging techniques can be divided into two main groups. The first group emphasizes brain structure or anatomy and utilizes computerized axial tomography (CT) and magnetic resonance imaging (MRI). The second group emphasizes brain functions, including blood flow, metabolism, and receptor activity utilizing functional magnetic resonance imaging (fMRI), magnetic resonance spectroscopy (MRS), positron emission tomography (PET), and single-photon emission computerized tomography (SPECT).

Computerized Tomographic Scan Studies

CT enables clinicians and researchers to examine the entire brain in vivo for the first time. The technology involves using standard x-rays directed at many angles toward the individual's brain. Special radiation sensors within the CT scanner generate a small electrical impulse. A computer then reconstructs the image that delineates white and gray matter, cerebrospinal fluid (CSF), bone, blood, and pathological tissues or areas. CT scans can also use intravenously injected contrast material to get a better delineation of brain areas.

CT studies have identified gross abnormalities (e.g., porencephalic cyst) in a minority of autistic patients. However, other findings from CT studies were contradictory and inconsistent. Some studies that showed abnormalities, such as reversed hemispheric asymmetry and ventricular enlargement had been challenged by other studies that have not reported such abnormalities (reviewed by Tsai, 1999).

Magnetic Resonance Imaging Studies

MRI utilizes nuclear magnetic resonance (NMR) technology, which measures electrical energy caused by high-strength radio frequency disturbing the bipolar alignment of atoms. White matter, gray matter, CSF, blood, and diseased tissue all differ in MRI measures, allowing excellent anatomic separation of the various normal and pathological components of the central nervous system. MRI has much strength compared to CT scanning. It requires no ionizing radiation, and quality imaging can be obtained without contrast injections. Although CT scanning is limited to one plane, the magnetic resonance technique can provide images in three planes: sagittal,

coronal, and transversal. It is free of bony artifacts. It can permit better visualization of relatively tiny structures. It also allows better delineation of the posterior fossa, a region that is observed with many bony artifacts on a CT scan. Also, fine shades of tissue abnormality (e.g., plaques in multiple sclerosis) can be better identified with this technique. Because of these advantages, it is rapidly replacing CT scanning as the method of choice for obtaining detailed anatomical information about the brain.

MRI studies in autistic subjects have reported cerebellar hypoplasia or a small brainstem including the midbrain, pons, and medulla oblongata; smaller amygdale; reduced size of corpus callosum; enlarged brains (temporal, parietal, and occipital lobes; reviewed by Tsai, 1999); smaller area dentate within the limbic system (Saitoh, Karns, & Courchesne, 2001); reduced volume of the hippocampus (Aylward et al., 1999); smaller right anterior cingulated gyrus; significantly increased total brain, total tissue, and total lateral ventricle volumes; increased volume of the caudate nuclei (Sears et al., 1999); increased total volume of cerebellum and cerebellar hemispheres (Hardan, Minshew, Harenski, & Keshavan, 2001). Other studies, however, have not found any abnormalities in the posterior fossa structures of the brain, particularly of the cerebellum, and in the hippocampus (reviewed by Tsai, 1999). Carper, Moses, Tigue, and Courchesne (2002) noted that there were several regions that showed signs of gray- and white-matter hyperplasia, as much as 20% enlargement, in 2- and 3-year-old children with autism. The frontal lobe showed the greatest enlargement, whereas the occipital lobe was not significantly different from that of healthy subjects. However, gray- and white-matter differences were not found in the older children.

Harris, Courchesne, Townsend, Carper, and Lord (1999) studied the neuroanatomic contributions to slowed orienting of attention in autistic children. The degree of slowed attention orienting to visual cues was significantly correlated with the degree of cerebellar hypoplasia. Pierce and Courchesne (2001) reported that measures of decreased exploration were significantly correlated with the magnitude of cerebellar hypoplasia of lobules VI–VII, and measures of rates of stereotyped behavior were significantly negatively correlated with area measures of cerebellar lobules VI–VII and positively correlated with the frontal lobe volume in autistic subjects. In a study of 22 boys with low-functioning autism, Elia et al. (2000) reported that there was a significant negative correlation between the midsagittal area of the cerebrum and age, and a positive correlation between the midsagittal area of the midbrain and some subscales of the Psychoeducational Profile—Revised. Howard et al. (2000) found that people with high-functioning autism had neuropsychological profiles characteristic of effects of amygdale damage, and that the same individuals also had abnormalities of medial temporal lobe brain structure, notably bilateral enlarged amygdale volumes.

On the other hand, Ciesielski and Knight (1994) found that the abnormal MRI cerebellar morphology was similar for both the high-functioning autistic subjects and the survivors of childhood leukemia treated with radiation and intrathecal chemotherapy. Furthermore, Schaefer et al. (1996) reported that hypoplasia of cerebellar vermal lobules VI and VII had also been noted under several conditions without autistic behavior. Thus, the reports of abnormal MRI macromorphology of the vermis may be nonspecific to autism. Hence, definitive conclusions concerning cerebellar vermal pathology in autism have not been clearly established.

In summary, different results in the MRI studies may have been due to patient's age, cognitive functioning level, size of study sample, and the method of area measurement. Nonetheless, the finding of abnormalities of the cerebellum is consistent with microscopic postmortem findings as described earlier. Although the link between the cerebellar abnormalities and autism has yet to be determined, MRI technology has provided an exciting new avenue for future in vivo studies of the brain.

Functional Magnetic Resonance Imaging Studies

Functional neuroimaging is usually based on the premise that the differences among the images of the brain obtained in different mental or functional states can reveal the differential involvement of various brain structures in particular activities. The signal changes of fMRI reflect changes in blood flow and oxygen concentration that are an indirect measure of neuronal activity. Because the subject is required to remain still while performing some tasks during scanning, only a few fMRI studies have been done in individuals with high-functioning autism.

Using fMRI and a test of judging from the expression of another person's eyes what that other person might be thinking or feeling, Baron-Cohen et al. (1999) found patients with autism activated the frontotemporal regions but not the amygdale. These results seem to provide support for the social brain theory of normal function and the amygdale theory of autism.

Ring et al. (1999) employed the Embedded Figures Task (EFT) and fMRI to study autistic patients' brain-activation patterns. Although the normally developed controls activated prefrontal areas, the autistic subjects showed greater activation of ventral occipitotemporal regions. The findings suggest that normally developed people invoke a greater contribution from working memory system, whereas the autistic subjects depend to an abnormally large extent on visual systems for object feature analysis.

Critchley et al. (2000) found that autistic subjects differed significantly from controls in the activity of cerebellar, mesolimbic, and temporal lobe cortical regions of the brain when processing facial expressions. Autistic

subjects did not activate a cortical "face area" when explicitly apprasing expressions, or the left amygdale region and left cerebellum when implicitly processing emotional facial expression.

Using fMRI during visually paced finger movement, Muller, Pierce, Ambrose, Allen, and Courchesne (2001) found that in general the autistic group had less pronounced activation compared to the controls. The controls showed greater activation in perirolandic and supplementary motor areas, whereas the autistic group had greater activation in the posterior and prefrontal cortices.

Luna et al. (2002) found that autistic subjects showed significantly less task-related activation in the dorsolateral prefrontal cortex (Brodmann area [BA] 9/46) and posterior cingulated cortex (BA 23) in comparison with healthy subjects during spatial working memory tasks. It is speculated that the impairments in executive cognitive processes in autism may be subserved by abnormalities in the neocortical circuitary.

Allen and Courchesne (2003) reported that while performing motor and attention tasks, the fMRI of autistic individuals showed significantly greater cerebellar motor activation and significantly less cerebellar attention activation than that of the healthy comparison subjects. The findings seem to suggest that developmental cerebellar abnormality has differential functional implications for cognitive and motor systems.

In summary, fMRI does provide information relating to brain activities and functions of certain brain structures; it brings us closer to understanding what brain deficits or dysfunctions may be involved in individuals with high-functioning autism. It, however, does not provide further information on what may be the cause(s) of autism.

Magnetic Resonance Spectroscopy Studies

Magnetic resonance spectroscopy (MRS) is a fairly new research technology that has potential to provide insights into the molecular metabolic pathology of neuropsychiatric disorders. Minshew, Goldstein, Dombrowski, Panchaligam, and Pettegrew (1993) used MRS to study 11 high-functioning autistic individuals. The pilot study found that the autistic group had decreased levels of phosphocreatine and esterified ends. As neuropsychological and language test performance of these subjects declined, levels of the most labile energy phosphate compound and of membrane building blocks decreased, and levels of membrane breakdown products increased. These results indicate alterations in brain energy and phospholipid metabolism in autism that correlate with neuropsychological and language deficits. The findings also seem to be consistent with neuropathological and neurophysiological findings in autism. Otsuka, Harada, Mori, Hisaoka, and Nishitani

(1999) used MRS to examine the right hippocampus-amygdala region and the left cerebellar hemisphere of 27 autistic patients, aged 2 to 18 years. The *N*-acetyl aspartate (NAA) concentration was significantly decreased. It was speculated that the decreased NAA concentration might be due to neuronal hypofunction or immature neurons. Chugani, Sundram, Behen, Lee, and Moore (1999) reported that autistic children had lower levels of NAA in cerebellum.

Positron–Emission Tomography Studies

PET is composed of three equally important subunits: a cyclotron, a radiopharmaceutical laboratory, and the actual imaging camera system. The cyclotron is used to produce short-lived radioisotopes of carbon (^{11}C), nitrogen (^{13}N), oxygen (^{15}O), and fluorine (^{18}F). The radioisotope containing the tracer is usually injected intravenously, and the injected tracer yields a positron. When this positron encounters an electron, it produces electromagnetic energy that is used to produce PET images of a three-dimensional view of a variety of biochemical processes such as brain energy, metabolism, regional blood volume, blood flow, tissue drug levels, and receptor binding. The functional and physiological information obtained by PET is quite different from that collected via CT or MRI and may be more useful for patient management (e.g., medication treatment effect can be monitored by PET information).

Earlier PET studies reported no significant differences in mean cerebellar glucose metabolism between adult patients with autism and age-matched control subjects nor substantially elevated utilization of glucose throughout many parts of the brain of autistic men compared with control subjects (reviewed by Tsai, 1999)

Siegel et al. (1992) used [^{18}F]fluoro-2-deoxyglucose PET to assess the regional cerebral glucose metabolic rate (GMR) in 16 high-functioning adults with autism and in 26 healthy individuals. Individuals with autism had a left-side greater than a right-side anterior rectal gyrus asymmetry, as opposed to the normal right-side greater than the left-side asymmetry in that region. The group with autism also showed low GMR in the left posterior putamen and high GMR in the right posterior calcarine cortex. Brain regions with GMR greater than 3 *SD*s from the normal mean were more prevalent in the group with autism than in the control group. In a later study, Siegel et al. (1995) found that in a group of adults with autism, there was a negative correlation of medial frontal cortical GMR with sustained attentional performance (i.e., the degraded stimulus continuous performance test), suggesting that neuronal inefficiency in that region may contribute to the poor performance.

Schifter et al. (1994) used [^{18}F]fluoro-2-deoxyglucose PET, MRI, and CT to study 13 autistic children. Four of the 13 patients had both abnormal PET and abnormal MRI, whereas 7 of the 13 patients had both normal PET and normal MRI or CT. Two patients with anatomical anomalies were noted only after knowledge of the PET findings.

Zilbovicius et al. (2000) reported that autistic patients tended to have a highly significant hypoperfusion in both temporal lobes centered in associative auditory and adjacent multimodal cortex. Haznedar et al. (2000) noted significant glucose metabolic reductions in both the anterior and the posterior cingulated gyri.

Using PET to study five high-functioning autistic adults, Muller et al. (1998) found the activation in the right dentate nucleus and in the left frontal area 46 was reduced during verbal auditory and expressive language and enhanced during motor speech. This finding may indicate impairment of dentatothalamocortical pathway. Muller et al. (1999) also reported a reversed hemispheric dominance during verbal auditory stimulation; a trend toward reduced activation of auditory cortex during acoustic stimulation; and reduced cerebellar activation during nonverbal auditory perception and possibly expressive language. These findings were considered as compatible with previous findings of cerebellar anomalies.

In a study of serotonin synthesis in the dentatothalamocortical pathway in seven boys and one girl with autism, Chugani et al. (1997) found asymmetries of serotonin synthesis in the frontal cortex, thalamus, and dentate nucleus of the cerebellum in all seven boys, but not in the one girl. Decreased serotonin synthesis was found in the frontal cortex and thalamus in five of the seven boys, and in the right frontal cortex and thalamus in the two remaining boys. In all seven cases, elevated serotonin sysnthesis in the contralateral dentate nucleus was observed. These serotonergic abnormalities in a brain pathway were considered as one mechanism underlying the pathophysiology of autism.

Although the meaning of the previously described findings remains to be determined, it appears that PET should become increasingly important for researchers studying autism.

Single-Photon Emission Computed Tomography Studies

A SPECT study uses radioisotope Xenon inhalation to provide a three-dimensional computerized tomographic representation of regional cerebral blood flow (rCBF). This is a noninvasive, painless, and safe procedure that does not take much time. It has wide applications in all age groups and can be easily used as a follow-up procedure with minimal exposure to radiation. The rapid acquisition of data and speedy washout of the tracer

from the brain allow repeated measurements within a short period of time, which is advantageous in patient-activation studies (Kuperman et al., 1990).

Zilbovicius et al. (1992) measured regional cerebral blood flow (rCBF) with SPECT in 21 autistic children; no cortical regional abnormalities were found. In another study of 5 autistic children, Zilbovicius et al. (1995) used SPECT twice during the children's development: at age 3 to 4 years and 3 years later. A transient frontal hypoperfusion was found in the autistic children at age 3 to 4 years. However, by age 6 to 7 years, these children's frontal perfusion had attained normal values. These results indicate a delayed frontal maturation in childhood autism.

George, Costa, Kouris, Ring, and Ell (1992) used SPECT to study four autistic young adults and four nonautistic age-matched control subjects. Total brain perfusion was significantly decreased in the autistic subjects. The autistic group had significantly decreased blood flow in the right lateral temporal and right, left, and midfrontal lobes compared with control subjects.

Chiron et al. (1995) used SPECT to study 18 children from 4 to 17 years with autism 10 age-matched controls. The rCBF in autistic subjects was decreased in the left hemisphere, particularly in the region of the sensorimotor- and language-related cortex. This result seems to support the notion of left hemispheric dysfunction in autism, especially in the cortical areas related to language and handedness.

Mountz, Tolbert, Lill, Katholi, and Liu (1995) used SPECT to investigate the rCBF in six young, severely impaired autistic children. Abnormally low rCBF values were found in the temporal and parietal lobes, with the left cerebral hemisphere showing greater rCBF abnormalities than the right.

Starkstein et al. (2000) used SPECT to measure rCBF of 30 autistic patients and noted significantly low perfusion in the following brain regions: right temporal lobe (basal and inferior areas), occipital lobes, thalami, and left basal ganglia. Wilcox, Tsuang, Ledgen, Algeo, and Schnurr (2002) found significant hypoperfusion in the prefrontal areas of 14 autistic subjects as compared to healthy controls. As the age of the autistic individuals increased, the hypoperfusion of verbal-associated areas in the left temporal lobe and frontal areas became more evident. It appeared that the changes in perfusion over time correlated with language development and acquisition as individuals matured. It is concluded that autistic individuals have a deficiency in prefrontal areas associated with word identification and language formation skills.

Hashimoto et al. (2000) performed SPECT in 22 autistic patients and reported the rCBF in both laterotemporal and dorsomediolateral areas decreased significantly in autistic patients. The rCBf was significantly higher in the right temporal and right parietal lobes than that in the left ones. Inversely, the rCBF in the frontal and occipital lobes was significantly higher on the left side than on the right side. A positive correlation between rCBF

and IQ was observed in the left laterotemporal and both dorsomediolateral frontal areas, and a negative one was noted in the cerebellar vermis area.

Ohnishi et al. (2000) assessed the relationship between rCBF and symptom profiles in 23 autistic children and found decreased rCBF in the bilateral insula, superior temporal gyri, and left prefrontal cortices. Impairments in communication and social interaction were thought to be related to the altered perfusion in the medial prefrontal cortex and anterior cingulated gyrus, and the obsessive desires for sameness were associated to altered perfusion in the right medial temporal lobe.

Kaya et al. (2002) used SPECT to study 18 autistic children and 11 nonautistic controls. Hypoperfusion in rCBF in autistic children compared with the control group was identified in the bilateral frontal, frontemporal, temporal, and temporo-occipital regions. There was no relationship between rCBF and the scores of the Ritvo–Freeman Real Life Rating scale. There was a relationship between the bilateral frontal region perfusion and the age of autistic children. There was also a negative correlation between IQ levels and other variables including scores of sensory responses, social relationship to people, and sensory–motor responses.

It is quite clear that further SPECT studies in individuals with autism are needed before more consistent findings emerge.

STUDIES OF NEUROPHYSIOLOGICAL FACTORS

There are two rather disparate neurophysiological hypotheses of autism. The first, which considers a primary cortical dysfunction in autism, emphasizes the autistic symptoms of language and communication and assumes an underlying specific cognitive disorder that is presumably of cortical origin. More specifically, this hypothesis considers that autism results from a disorder of hemispheric lateralization; that is, the neural substrates in the left hemisphere necessary for sequential forms of information processing fail to develop (reviewed by Tsai, 1999).

A second hypothesis proposes a primary brainstem dysfunction in autism. This hypothesis has been developed through observation of the impaired ability of children with autism in modulating their own responses to sensory input and consequently their own motor output. This hypothesis suggests a rostrally directed sequence of pathophysiological influences originating in the brain, substantia nigra, and the nonspecific nuclei of the thalamus (reviewed by Tsai, 1999).

The cortical dysfunction hypothesis of autism has received some support from the fact that a significant proportion of people with autism have electroencephalographical (EEG) abnormalities. In general, these abnormalities tend to involve bilateral brain hemispheres and are characterized

by focal or diffused spike, slow wave, or slow dysrhythmic patterns. The type of abnormality does not appear to be specific (reviewed by Tsai, 1999). The cortical dysfunction hypothesis is also supported by the event-related brain potential (ERP) study which demonstrated an abnormally small amplitude of the p3b, a component of the ERP; by sleep EEG studies that found the eye movements of children with autism were more like those of healthy infants than like those of age-matched controls; by computerized quantitative EEG studies, indicating an abnormal pattern of cerebral lateralization in individuals with autism; by several auditory evoked-response studies of children with autism indicating maturational deviation and markedly smaller amplitude of N1c wave at bitemoral sites and pronounced peak latency delay (around 20 ms), particularly on the left side of the superior temporal gyrus (reviewed by Tsai; Bruneau, Roux, Adrien, & Barthelemy, 1999). However, a recent study of P50 gating (caused by the excitability of the neuronal substrate) found no difference between the 12 nonretarded children with autism and the 11 healthy control children (Kemner, Oranje, Verbaten, & van Engeland, 2002).

The hypothesis of brainstem dysfunction in autism is somewhat supported by autonomic response studies, vestibular nystagmus studies (except in the high-functioning autism that seems to have normal postrotary nystagmus as reported by Goldberg, Landa, Lasker, Cooper, and Zee (2000), and brainstem auditory evoked-potential studies (e.g., prolongation of the early auditory-evoked response interpeak latencies) (reviewed by Tsai; Maziade et al., 2000).

STUDIES OF NEUROCHEMICAL FACTORS

Three main reasons responsible for the recent increase in interest in neurochemical studies in autism are a lack of gross brain pathology, suggesting that microscopic or functional factors may be responsible for autism; relative success in the pharmacological treatments for certain limited aspects of autism; and recent advances in basic neurosciences as applied to psychiatric disorders. There is now evidence supporting the notion that abnormal behavior involves abnormal neural communication in the form of abnormal metabolism or function of neurotransmitters (chemical substances responsible for the transmission of signals between synapses). Neuroscientists have identified several types of neurotransmitters: catecholamine transmitters (epinephrine, norepinephrine, and dopamine), serotonin, acetylcholine, γ-aminobutyric acid, and certain other amino acids and neuropeptides. Undoubtedly, many more remain to be found.

Neuroscientists have found that too much of the neurotransmitter dopamine in the brain's emotion centers (limbic system) and too little in the seat of reason (i.e., brain cortex) may cause suspiciousness and an inability

to process the information contained in the rhythms and cues of social interaction. Without enough dopamine, working memory (which stores information while the mind considers whether it is worth keeping and how to file it) falters. Altered central dopaminergic function in the midbrain is now considered the principal neurotransmitter system implicated in the pathogenesis of Tourette syndrome.

It has been found that a shortage of serotonin in the frontal lobes and in the brain's limbic system (where emotions originate) seems to relate to impulsivity and the person becoming unable to connect disagreeable consequences with what provoked them. A serotonergic defect involving basal ganglia may cause obsessive-compulsive symptoms in some people.

Neuroscientists have noted that inhibited children may have excessive levels of norepinephrine and much less is required to stimulate the amygdala (controls heart rate and perspiration) of an inhibited child. On the other hand, a shortage of norepinephrine seems to weaken a person's ability in paying attention to what's important.

These intriguing observations have led researchers to the studies of major neurotransmitters in autism. Although the studies are usually preliminary and often compounded by problems inherent in neurochemical research (such as assay methods, measurements of body fluids, confounding variables of age, sex, etc.), the overall evidence strongly suggests that neurochemical factors play a major role in the presentation of autism. The following section focuses on each of the major neurotransmitters separately, although there is a considerable overlap between their functions.

Serotonin Studies

Serotonin (5-hydroxytryptamine or 5-HT) is an important neurotransmitter whose activity has been implicated in a variety of important processes, such as body temperature regulation, pain, sensory perception, immune response, sleep, sexual behavior, motor functioning, neuroendocrine regulation, appetite, and learning and memory. It is synthesized from the amino acid tryptophan and metabolized to 5-hydroxyindoleacetic acid. The serotonergic system has most of its cell bodies in the hindbrain from where they projected widely to other parts of the brain. Apart from the brain, serotonin is also found in the intestine and blood platelets.

Many studies have consistently reported that about one third of individuals with autism have hyperserotonemia. There are three possible explanations for the hyperserotonemia: (a) enhanced platelet uptake, storage, or platelet volume; (b) increased synthesis; and (c) decreased catabolism.

Geller, Yuwiler, Freeman, and Ritvo (1988) reported no significant difference in platelet volumes between autistic patients and control subjects. The platelet volumes and blood 5-HT concentration also did not correlate.

Studies had reported that the platelets' handling of serotonin (5-HT) appeared to be normal in autism; that the probands with autism and their first-degree relatives had a strong familial resemblance and there was a positive correlation of both platelet-rich plasma 5-HT and platelet-poor (free) plasma 5-HT between the probands with autism and their first-degree relatives; that the platelet-rich plasma 5-HT levels of individuals with autism with affected siblings (i.e., with either autistic disorder or pervasive developmental disorders not otherwise specified [PDDNOS]) were significantly higher than these the individuals with autism without affected siblings, and individuals with autism without affected siblings had 5-HT levels significantly higher than did controls, suggesting that 5-HT levels in individuals with autism may be associated with genetic liability to autism (reviewed by Tsai, 1999). McBride et al. (1998) found that autistic youngster had significantly higher 5-HT plasma concentrations than did controls, and that white children had significantly lower 5-HT levels than did black or Latino youngsters. Postpubertal subjects had lower 5-HT concentrations than did prepubertal subjects. These findings suggest that future studies need to pay attention to the importance of controlling and matching for race and pubertal status.

Marazziti et al. (2000) investigated the 5-HT transporter by means of the specific binding of [^{3}H]-Paroxetine ([^{3}H]-Par in 20 autistic children and adolescents. The results showed a significantly higher density of [^{3}H]-Par binding sites in autistic subjects than those in healthy controls, suggesting the presence of serotonergic dysfunction in autism.

The studies of 5-HT synthesis in autism have been conflicting. Several studies have not found any difference between individuals with and those without autism (reviewed by Tsai, 1999). However, Croonenberghs et al. (2000) recently found the plasma concentrations of tryptophan, the precursor of 5-HT, were significantly lower in 13 postpubertal autistic patients than in healthy controls. Nevertheless, there was no significant difference among the groups in the serum concentration of 5-HT. The serum tryptophan to large neutral amino acids ratio (Try/LNAA) is considered a reliable marker of tryptophan availability for brain serotonin synthesis. D'Eufemia et al. (1995) found a significantly lower serum Try/LANN ratio in the autistic subjects compared to that in the normally developed controls. It is suggested that low brain tryptophan availability due to a low serum Try/LNAA ratio could be one of the possible mechanisms involved in the alteration of serotonergic function in autism.

The occurrence of hyperserotonemia in people with autism does not appear to be the result of decreased catabolism of serotonin.

Although there was a preliminary finding of negative correlation between whole-blood 5-HT and verbal-expressive or symbolic abilities in 18 patients with autism and their first-degree relatives, no consistent correlations have yet been found between blood serotonin levels and any autistic behaviors or

symptoms. Moreover, hyperserotonemia has also been found in some children who are severely retarded. Clearly, the mechanism and importance of hyperserotonemia in autism remain unclear. Furthermore, the CSF concentration of serotonin metabolite, 5-hydroxyindoleacetic acid (5-HIAA), in children with autism was not significantly different from that seen in the control group of nonneurologically impaired children (reviewed by Tsai, 1999).

Dopamine Studies

Dopamine is synthesized from the amino acids phenylolamine and tyrosine and metabolized to homovanillic acid (HVA) and dihydroxyphenylacetic acid. The dopaminergic system has most of its cell bodies in the midbrain and is particularly important in the regulation of motor functioning, neuroendocrine regulation, cognition, eating and drinking behaviors, sexual behavior, and selective attention. It has been reported that neuroleptics, which are dopamine receptor-blocking agents, modulate several symptoms involving the motor system (e.g., hyperactivity, stereotypies, aggression, and self-injury) and make children with autism more compliant and receptive to special education procedures. On the other hand, dopamine agonists, such as stimulants, cause a worsening of preexisting stereotypies, aggression, and hyperactivity in children with autism. These observations strongly suggest a role of dopamine system in autistic symptomatology (reviewed by Tsai, 1999).

Studies of dopamine in autism have focused on the measurement of HVA, the main metabolite of dopamine. Previous studies have reported that the autistic children did not differ from other diagnostic groups in CSF level of HVA, though the CSF level of HVA was found to be higher in the more severely impaired children, especially those with greater locomotor activity and more severe stereotypies; that no difference existed in CSF HVA between "child psychosis (largely autism)" and "perceptual cognitive disorder" diagnostic groups; that there were elevated CSF HVA levels in autistic subjects; that no difference existed in plasma HVA between the autistic children and the control subjects; that HVA concentrations have not been shown to correlate with any autistic behaviors or symptoms (reviewed by Tsai, 1999).

Epinephrine and Norepinephrine Studies

Epinephrine and norepinephrine are often discussed concurrently because of their similar effects on behavior. They are associated with cardiovascular function, respiratory function, appetite, activity level, arousal, attention, anxiety, response to stress, movement, sleep, memory, and learning

(Young et al., 1982). Norepinephrine acts as a central and peripheral neurotransmitter and is synthesized from dopamine by the action of the enzyme dopamine β-hydroxylase (DBH). Most of the neurons are located in the hindbrain. Central norepinephrine is metabolized to 3-methoxy-4-hydroxyphenylglycol (MHPG), whereas peripheral norepinephrine gets converted to both MHPG and vanillylmandelic acid (VMA). The adrenal medulla is the site of synthesis of most of the peripheral epinephrine (reviewed by Tsai, 1999).

Studies of epinephrine and norepinephrine have reported that plasma norepinephrine was elevated in individuals with autism, but in platelets both epinephrine and norepinephrine were significantly lower in the group with autism as compared with the control group; and that there uses no difference in CSF, plasma, and urinary excretion MHPG; and in urinary excretion rates of epinephrine, norepinephrine, and VMA between people with autism and controls (reviewed by Tsai, 1999).

Other Monoamines Studies

It has been reported that the urinary levels of dopamine and its derivatives HVA, 3-4 dihydroxyphenylacetic (DOPAC), 3-methoxytyramine (3-MT), epinephrine, norepinephrine, and serotonin and its metabolite 5-HLAA in children with autism aged 2 to 12 years, 6 months were decreased significantly with age. The results seem to suggest a maturation defect of the monoaminergic system in autism (reviewed by Tsai, 1999).

Dopamine β-Hydroxylase Studies

Conflicting results have been reported on the study of DBH, the enzyme that controls the conversion of dopamine to norepinephrine. Some investigators found a decreased DBH activity in patients with autism as compared with that in controls, whereas other investigators found no difference of DBH activity in the autistic group (reviewed by Tsai, 1999). The real meaning of blood DBH activity is unclear, because healthy humans also exhibit a wide range of this activity without evident effect.

Peptides Studies

Certain peptides have been shown to act as neurotransmitters and affect pain perception, emotion, appetite, and sexual behavior. An earlier study reported a number of different urinary peptides' profile patterns, each said to be characteristic of a different behavioral abnormality. However, in an

attempt to replicate such a finding, no consistent patterns of urinary chromatographic profile were identified (reviewed by Tsai, 1999). A recent study by Hunter, O'Hare, Herron, Fisher, and Jones (2003) questions the validity of the opioid peptide excess theory for the cause of autism. Nevertheless, the findings are intriguing, and further study may develop patterns with high specificity that may be used as diagnostic markers. Any isolation and identification of any factors present in the chromatographic fractions may also contribute to the understanding of the pathogenesis of autism.

Brain Opioids Studies

Certain peptides, such as enkephalins and endorphins, appear to act as endogenous opioids. An endorphin hypothesis has been proposed based on the analogy between opiate addiction and autism and the similarity between opiate-induced psychosocial distortion in animals and clinical manifestations of autism. Studies of brain opioids in autism have reported higher levels of CSF β-endorphin in baseline measures of autistic children compared with those in control samples; low levels of CSF β-endorphin in autistic subjects; CSF levels of β-endorphin in autistic subjects did not differ from those of age-matched controls; low levels of plasma β-endorphin in autistic individuals; increased plasma β-endorphin levels in autistic subjects; and familial aggregation of elevated plasma β-endorphin levels. The β-endorphin levels of the autistic patients with severe self-injurious behavior were significantly lower than those of autistic subjects without self-injurious behavior, suggesting that severe self-injurious behavior plays a more significant role than does autism in the plasama β-endorphin levels (reviewed by Tsai 1999).

Although the role of brain opioids in autism is unclear, there is a need for further research in this field because of the clinical efficacy of opioid antagonists in the control of some autistic symptoms.

Studies of Other Biochemical Factors

A number of other abnormal biomedical measures in people with autism have been reported: significantly lower blood adenosine triphosphatase activity in assays of red blood cells from children with autism; an elevated CSF creatine phosphokinase activity in some children with autism as well as in children with meningitis, a finding suggesting that children with autism with an increased CSF creatine phosphokinase may represent a subgroup of children whose autism is due to brain insult from infection; significantly decreased amino acids: aspartic acid, glutamine, glutamic acid, and γ-aminobutyric acid; the mean plasma glutamic, aspartic acid, and taurine values elevated in autistic children; the significantly increased CSF glial

fibrillary acidic protein in autism and autistic-like conditions; the significantly lower mean TSH basal and peak levels in patients with autism compared to those of the controls; the finding that plasma levels of testosterone and adrenal androgen were normal in postpubertal individuals with autism and the significantly increased concentrations of CSF gangliosides in autistic subjects (reviewed by Tsai, 1999). Recently, Page and Coleman (2000) suggested that about 20% of autistic patients are hyperuricosuric individuals and that their purine synthesis is increased.

In summary, although a variety of neurochemical abnormalities have been reported in autism, the neurochemical variables being examined are usually collected from blood or urine, which are rather remote from either brain function or structure. Thus, the meaning and significance of the findings are not clear. Nevertheless, this is an important topic for further research in order to improve our understanding of the etiological role of neurochemical factors, as well as to enhance the development of effective medication treatment in autism.

IMMUNOLOGICAL STUDIES

Several studies have suggested the possibility of an immune defect in autism. Earlier studies reported findings that include no support of a slow virus playing a role in autism, an increased frequency of autism in individuals with congenital rubella, or an association between autism and prenatal rubella or influenza infection in about 5% of autistic patients; reduced responses to T-cell mitogen concanavaline A, a reduced response to B-cell mitogen pokeweed, a decreased number of T lymphocytes and an altered helper or T-suppressor cell ratio; about 40% of subjects with autism had significantly reduced activity of natural killer cell (a large granular lymphocyte and a likely part of a basic defense mechanism against virus-infected cells and malignancy); a significantly decreased plasma concentration of the C4B protein; DR+ T cells, an indicator of activated T cells, were inversely correlated with a decreased plasma level of the C4B protein; 76% of autistic patients exhibited inhibition of macrophage migration, suggesting a cell-mediated autoimmune response to brain antigens existed 58% individuals with autism were positive for antibodies to myelin basic protein (MBP), a component of myelin—a rate more than six times higher than that in the controls; and about one third of the children with autism had an unusual antibody circulating in their blood and spinal fluid (reviewed by Tsai, 1999).

Denney, Frei, and Gaffney (1996) reported that children with autism had a lower percentage of helper-inducer cells and a lower helper:suppressor ratio, with both measures inversely related to the severity of autistic symptoms.

Scifo et al. (1996) found that naltrexone improved autistic children's behaviors and caused alterations in the distribution of the major lymphocyte subsets, with a significant increase of the T-helper inducers (CD4+CD8−) and a significant reduction of the T-cytotoxic suppresor (CD4+CD8+) resulting in a normalization of the ratio CD4: CD8. The finding is interpreted as that the mechanism underlying opioid-immune interactions are altered and may play a role in the development of autism. Gupta, Aggarwal, Rashanravan, and Lee (1998) examined Th1-like and Th2-like cytokines in CD4+ and CD8+ T cells in children with autism, and found an imbalance of Th1-like and Th2-like cytokines in the autistic children. The finding was speculated as possible cause of autism. Recently, Croonenberghs, Bosmans, Deboutte, Kenis, and Maes (2002) reported an increased production of proinflammatory cytokines in children with autism and speculated that it could play a role in the cause of autism.

Singh, Warren, Averett, and Ghaziuddin (1997) found a significant increase in the incidence of autoantibodies to neuron–axon filament protein (anti-NAFP) and autoantibodies to glial fibrillary acidic protein (anti-GFAP) in autistic subjects. It was speculated that these autoantibodies might be related to the autoimmune pathology of autism. Singh, Lin, and Yang (1998) further reported an association between virus serology and brain autoantibody in autistic subjects and proposed a hypothesis that virus-induced autoimmune response might play a causal role in autism. Connolly et al. (1999) found IgG antibrain autoantibodies in 27% of sera and IgM autoantibodies in 36% of sera from children with autistic spectrum disorder. The findings were speculated as that autoimmunity might play a role in the pathogenesis of language and social development abnormalities in a subset of children with autism. Torrente et al. (2002) found a novel form of ebteropathy in autistic children, in which increases in the mucosal lymphocyte density and crypt cell proliferation occur with epithelial IgG depositin. The features are considered as an autoimmune lesion in children with regressive autism. Monoclonal antibody D8/17-positive cells were found in 78% of 18 patients with autism. As severity of repetitive behaviors significantly correlated with D8/17 expression, Hollander et al. (1999) suggested that D8/17 expression could serve as a marker for compulsion severity within autism.

All these findings seem to suggest that depressed immune function, autoimmune mechanism, or faulty immune regulation (deficiency in some components of immune system and excesses in others) may be associated with the etiology of autism. However, the interpretation of the reported data is hampered by conceptual and methodological differences among studies. Both the clinical significance of the immune changes and the causal connection between immune changes and autistic symptoms remain to be elucidated by future more extensive studies.

GENETIC STUDIES

Major advances have been made over the past 2 decades in elucidating some of the underlying genetic and molecular mechanisms in a number of medical disorders (e.g., cystic fibrosis) and neurological disorders (e.g., Huntington's disease). Traditionally, twin, family, and adoption studies are the first step toward establishing evidence for a genetic involvement in a certain medical or neurological disorder. The second step is applying segregation analysis or linkage studies to determine the chromosomal location of the gene(s) of interest. Linkage studies can determine whether genes for a given disorder lie on a chromosome in close proximity to known genetic markers, such as the gene for colorblindness or for certain blood types. If two genes lie close together, the two traits they cause are likely to be inherited together. Finding clear evidence of linkage between a given psychiatric disorder and a trait caused by a known genetic marker would provide hard evidence that the psychiatric disorder is genetically induced and would lay to rest any doubts left by loopholes in twin and adoption studies. Furthermore, through the identification of genetic markers, a clearer pattern of genetic transmission may be elucidated, etiologic subgroups may be identified, and the pathophysiology of a disorder may be determined. Finally, molecular biological and recombinant DNA techniques are used to isolate the gene(s) with mutation that is (are) responsible for the disorder of interest. Because proteins are produced from the instructions in genes, a mutation in a gene that codes for a specific protein can affect the structure, regulation, function, or synthesis of the protein, which in turn causes a specific medical or neurological disorder. For example, utilizing this approach in medical genetics, different enzymatic defects have been identified to elucidate the existence of many subtypes of mucopolysaccharidoses.

Research since 1980 has demonstrated that, at least in a subgroup of autism, genetic factors play a major role in the predisposition to autism. This suggestion is made based mainly on data from family studies, twin studies, and chromosome disorders associated with autism. A delineation of just what is inherited will provide a better understanding of genetic implications in autism.

Several family studies have shown that between 2% and 6% of the siblings of children with autism suffer from the same condition. When this estimated sibling incidence is compared with the general population risk, the rate of autism in siblings is about 50 to 75 times higher. Family studies of autism also show that between 6% and 24% of the siblings of probands with autism have cognitive disorders (including autism, mental retardation, and learning disability) or speech–language disorders (reviewed by Tsai, 1999).

Twin studies have reported the concordant rate for autism in monozygotic twin pairs (MZ) ranged from 36% to 100%, and in dizygotic (DZ) twin pairs,

the rate ranged from 0% to 10%. When a broader spectrum of related cognitive or social abnormalities was applied to the sample, 92% of the MZ pairs were concordant for the spectrum, compared with 10% of the DZ pairs. The findings indicate that autism is under a high degree of genetic control and suggest that multiple genetic loci are involved. The findings also suggest that autism might develop on the basis of a combination of genetic predisposition and biological impairment (reviewed by Tsai, 1999).

Autism has been reported to be associated with various chromosomal abnormalities: a duplication of the short arm of chromosome X (Rao et al., 1994); deletion of the short arm of X chromosome (Thomas et al., 1999); supernumerary XYY (Nicolson, Bhalerao, & Sloman, 1998) and XXY (Konstantareas & Homatidis, 1999); partial duplication of the short arm of chromosome Y (Blackman, Selzer, Patil, & Van Dyke, 1991); translocation with both chromosomes X and 8 (Ishikawa-Brush et al., 1997); deletion of the distal portion of the long arm of chromosome 2 (2q37) (Ghaziuddin & Burmeister, 1999); 2q deletion (Wolff, Clifton, Karr, & Charles, 2002); chromosome 4 duplication (4)p12-p13 (Sabaratnam, Turk, & Vroegop; 2000); balanced translocation between chromosomes 4 and 12 (Nasr & Roy, 2000); translocation of chromosome 7 (Vincent et al., 2000); ring chromosome 7 (Schroer et al., 1998); partial duplication of the short arm of chromosome 11 (Herault et al., 1994); pericentric inversion of chromosome 12 (Schroer et al.); trisomy 13 (Konstantareas & Homatidis, 1999); balanced 13;16 translocation (Schroer et al.); partial trisomy of chromosome 15 (Gillberg et al., 1991); partial tetrasomy of chromosome 15 (Hotopf & Bolton, 1995), tetrasomy chromosome 15q11-q13 (Silva et al., 2002), chromosome 15q11–13 (Baker, Piven, Schwartz, & Patil, 1994), chromosome 18q (Seshadri, Wallerstein, & Burack, 1992); inversion–duplication of chromosome 15 (Borgatti et al., 2001; Flejter et al., 1996; Konstantareas & Homatidis, Schroer et al.); mosaic trisomy of chromosome 17 (Schaeffer et al., 1996); mosaicism for a duplication of the long arm and a deletion of the short arm of chromosome 18 (Ghaziuddin, Sheldon, Tsai, & Alessi, 1993); interstitial deletion of chromosome 20 (20p11.22–p11.23) (Michaelis et al., 1997; Schroer et al.); chromosomes 20/22 translocation (Carratala et al., 1998); Ring chromosome 22 (Assumpcao, Junior 1998; MacLean et al., 2000) and 22q13.3 deletion (Goizet et al., 2000); and complex chromosome rearrangement of chromosomes 1, 7, and 21 (Lopreiato & Wulfsberg, 1992). The significance of these associations is not clear because these findings are all from case reports. Nonetheless, these case reports may support the notion that autism is genetically heterogeneous and with variability of clinical features.

Some genetic syndromes are associated with some cases of autism. These syndromes include phenylketonuria, fragile X syndrome, and tuberous sclerosis. Some investigators have found a high prevalence of fragile X syndrome

in persons with autism, whereas others have failed to replicate this finding (reviewed by Tsai, 1999). About 20% to 25% of patients with tuberous sclerosis also meet criteria for autistic disorder (Baker, Piven, & Sato, 1998; Smalley, 1998). The mechanism underlying the association of autism and TSC is unclear. It is speculated that the presence of autism may arise if the TSC gene mutations occur at critical stages of neural development in neural tissue of brain regions critical in the development (Smalley). Steffenburg, Gillberg, Steffenburg, & Kyllerman (1996) found 4 out of 49,000 children were diagnosed to have Angelman syndrome. All 4 children with Angelman syndrome also met the full criteria for the diagnosis of autistic disorder. Maternal truncation mutation in the UBE3a/E6-AP gene in chromosome 15q11-13 has been known to cause Angelman syndrome. This finding suggests that the possible gene for autism may be identified in the 15q11-13 region (Herzing, Kim, Cook, & Ledbetter, 2001). Nevertheless, there is no clear evidence that these genetic syndromes cause autism.

Available data from the family and twin studies indicate that autism is genetically heterogeneous and that several genes are involved in the development of autism. Spence et al. (1985) failed to detect any significant linkage in a sample of 27 families with multiple children with autism and 7 families with one child with autism. However, they suggested that potential markers may be found in chromosome 9 in the region of the ABO blood group. The finding of fragile X chromosome among patients with autism led Tsai, Crowe, Patil, Murray, & Quinn (1988) to use six DNA probes in the Xg26-q28 region to search for DNA markers for autism. However, a clinically useful marker was not found.

With the recent advancement of molecular genetic techniques, several whole genome screenings for linkage have been carried out in several samples of multiplex families with autism (two or more autistic siblings). Strong evidence for linkage to autism has been identified on chromosomes 1p, 2q, 3, 4p, 4q, 5p, 6q, 7q, 8, 8q21.2, 10q, 11, 12, 15q11-q13, 16p, 17q, 18q, 19p, 19q, 22q, Xp (Auranen et al., 2000; Badner & Gershon, 2002; Borg et al., 2002; International Molecular Genetic Study of Autism Consortium [IMGSAC], 2001a; Liu et al., 2001; Philippe et al., 1999). Several studies seemed to exclude the genetic effect causing autism on the X chromosome (Hallmayer et al., 1996; Schutz et al., 2002), particularly at the Xq27.3 region (Klauck, Munstermann, et al., 1997); Y chromosome (Jamain et al., 2002); loci in the HLA region on chromosome 6p (Rogers et al., 1999); FOXP2 gene, located on chromosome 7 q31 (Newbury et al., 2002; Wassink et al., 2002); DOPA decarboxylase (DDC) gene (Lauritsen et al., 2002).

On the other hand, two chromosomes seem to emerge as the most prominent chromosomal region of interest: 7q and 15q. Several studies focused on chromosome 7q in autistic samples have been carried out and identified chromosome band 7q31-33 as the likely susceptibility locus (Ashley-Koch et al., 1999; Barrett et al., 1999; IMGSAC, 2001b; Warburton et al., 2000;

Wassink et al., 2001). Several studies have found evidence in support of linkage to the chromosome 15q11-13 region (Bass et al., 2000; Cook et al., 1998; Craddock & Lendon, 1999; Maddox et al., 1999; Martin et al., 2000; Repetto et al., 1998; Rineer, Finucane, & Simon, 1998; Wolper et al., 2000) and 15q22-23 region (Smith et al., 2000). Furthermore, the duplication of 15q11-13 was found to be maternally inherited (Cook, Lindgren, et al., 1997b; Martinsson et al., 1996; Schroer et al., 1998). Salmon et al. (1999), however, believed that the role of of 15q11-13 is minor, at best, in the majority of individuals with autism. Lauritsen et al. (1999) proposed some possible candidate regions on chromosomes 7q21 and 10q21.2.

Several candidate genes have been proposed to be associated with autism. Cook, Courchesne, et al. (1997) provided evidence of linkage and association between the serotonin transporter gene (HTT) in the 15q11-13 region and autism. Yirmiya et al. (2001) also showed evidence for an association with the serotonin transporter region polymorphism and autism. Other investigators, however, were not able to replicate the finding (Betancur et al., 2002; Klauck, Pouska, Benner, Lesch, & Poustka, 1997; Maestrini et al., 1999; Persico, Militerni, Bravaccio, Schneider, Melmed, & Conciatori, et al., 2000; Zhong et al., 1999). Tordjman et al. (2001) noted that transmission of HTT promoter alleles did not differ between probands with autism and their unaffected siblings. However, allelic transmission in probands was dependent on the severity of impairment in the social and communication domains. It was concluded that HTT promoter alleles by themselves do not convey risk for autism, but rather modify the severity of autism in the social and communication domains. Other candidate genes or genetic markers that have been proposed include: ATP10C in the 15q11-13 region (Herzing et al., 2001), GABA receptor gene in 15q11-13 (Buxbaum et al., 2002), c-Harvey-ras (HRAS) markers (Herault et al., 1995), Adenosine deaminase 2 (ADA2) alleles (Persico, Militerni, Bravaccio, Schneider, Melmed, & Trillo et al., 2000), Asn allele of the ADA Asp8Asn polymorphism (Bottini et al., 2001), HOXA1 (Ingram et al., 2000), longer triplet repeats in the 5' untranslated regions (5'UTRs) of the reelin (RELN) gene (Persico et al., 2001), GXAlu marker of the neurofibromatosis type 1 (NF1) gene (Mbarek et al., 1999), the third hypervariable region (HVR-3) of HLA-DR beta 1 alleles (Warren et al., 1996), glutamate receptor 6 gene (GluR6) (Jamain et al., 2002). All the proposed markers and candidate genes require careful replication studies to be considered as possibly playing a role in the development of autism. For example, HOXA1 and HOXB1 (Li et al., 2002) and ATP10C (Kim et al., 2002) genes have been found unlikely to play a significant role in the genetic predisposition to autism. Four candidate genes in the 7q32 region (i.e., PEG1/MEST, COPG2, CPA1, and CPA5) (Bonora et al., 2002) and 10 candidate genes (proenkephalin, prodynorphin, and protein convertase subtilisin/kexin type 2; tyrosine hydroxylase, dopamine receptors D2 and D5, monoamine oxidases A and B; brain-derived neutrophic factor, and

neural cell adhesion molecule) (Philippe et al., 2002) do not seem to play major roles in autism.

Regarding the mode of inheritance of autism, Ritvo et al. (1985), on the basis of a segregation analysis of 46 families with multiple cases of autism, produced results that were consistent with autosomal recessive inheritance. However, this is inconsistent with the observed marked excess of males with autism. Tsai and his colleagues (Tsai & Beisler, 1983) proposed a multifactorial model with different thresholds for males and females. Szatmari and Jones (1991) suggested an X-linked model. However, none of the proposed models can entirely explain the empirical data of autism. A major reason for the difficulty in the interpretation of data on the mode of inheritance is due to the lack of general agreement on the precise definition of the autism phenotype.

Szatmari et al. (1995) reported that rates of cognitive impairments and psychiatric symptoms were not found more frequently in parents or relatives of PDD probands compared to relatives of controls. Other investigators have reported that parents of autistic children had increased rates of anxiety disorder (Piven et al., 1991), major depressive disorder (Bolton, Pickles, Murphy, & Rutter, 1998; DeLong & Nohria, 1994; Piven & Palmer, 1999; Smalley et al., 1995), social phobia (Piven & Palmer; Smalley et al.), motor tics, and obsessive–compulsive disorder (Bolton et al.); and of particular characteristics such as rigidity, aloofness, hypersensitivity to criticism, and anxiousness; speech and pragmatic language deficits; and limited friendships (Piven et al., 1997). Murphy et al. (2000) noted there was a significantly increased expression of traits among the autism relatives such as anxious, impulsive, aloof, shy, oversensitive, irritable, and eccentric. Gillberg et al. (1992) reported that the mothers of autistic children tended to have schizoaffective disorder and that Asperger disorder was more common among first-degree relatives of children with autism compared with control subjects. The brothers of a group of autistic females were noted to have a lower verbal performance (Plumet, Goldblum, & Leboyer, 1995). Folstein et al. (1999) found parents of autistic children scored slightly but significantly lower on the WAIS-R (Wechsler Adult Intelligence Scale-Revised) Full Scale and Performance IQ Test, and on the Word Attack Test from the Woodcock–Johnson battery compared to the parents of controls. There was, however, no difference between siblings of the autistic group and the Down syndrome controls. Fombonne, Bolton, Prior, Jordan, & Rutter, (1997), however, reported that the parents and siblings of autistic probands had slightly superior verbal performance than the parents and siblings of Down syndrome controls. These findings suggest some association between autism and other major psychiatric disorders and verbal performance. However, more study is needed to gain a better understanding of the genetic implications of these major psychiatric disorders in autism.

In summary, since the mid-1980s, genetic research in autism has found strong evidence suggesting that there may be different genetic mechanisms that result in the syndrome of autism. Several different kinds of studies are needed in order to sort out the various mechanisms, and should begin with a detailed family study based on a systematically ascertained sample. Each proband with autism and all first-degree relatives should have a detailed clinical examination and laboratory tests including social, cognitive, and language assessment. The goal is to identify genetic markers so that the autism phenotype can be redefined using such markers. Then, comparative studies of individuals with and without autism who have the same subclinical markers (e.g., unaffected relatives) should be conducted. In this way, genotype–genotype interactions or genotype–environment interactions may be elucidated in the etiology of autism (Smalley et al., 1988). The ultimate goal is to be able to apply gene therapy to those who are affected with autism, as well as to be able to practice prevention of autism.

Several genome wide screens for susceptibility genes have been performed with limited concordance of linked loci. These data seem to indicate that either there are numerous genes of weak effect involved in the development of autistic disorder or that autistic disorder is genetically heterogeneous. Nonetheless, presently the most interesting chromosome regions concerning the etiology of autistic disorder are chromosomes 7q31-35, 15q11-13, and 16p13.3 (Lauritsen & Ewald, 2001).

STUDIES OF VACCINATION FACTOR

The hypothesis that measles, mumps, and rubella (MMR) vaccines cause autism was first raised by reports of cases in which developmental regression occurred soon after MMR vaccination. However, several major epidemiological studies failed to find any evidence to support a causal association between the MMR vaccine and autism (Farrington, Miller, & Taylor, 2001; Kaye, del Mar Melero-Montes, & Jick, 2001; Taylor et al., 1999). Concern has also been raised about a possible association between the MMR-vaccine-induced mercury (thimerosal) exposure and autism (Bernard, Enayati, Redwood, Roger, & Binstock, 2001). The available evidence, however, does not support such a hypothesis (Halsey, Hyman, & Conference Writing Panel, 2001; Madsen et al., 2002; Taylor et al., 2002).

STUDIES OF SEASON OF BIRTH FACTOR

Some investigators have proposed that birth in particular months may be a risk for autism. Barak, Ring, Sulkes, Gabbay, & Elizur, (1995) suggested

that March and August births may be risk factors for the development of autistic disorder in Israel. Stevens, Fei, and Waterhouse, (2000) noted a significant elevation in births in March within the Boston sample. However, other investigators failed to find such a finding (Landau, Cicchetti, Klin, & Volkmar, 1999; Yeates-Frederikx, Nijman, Logher, & Merckelbach, 2000).

STUDIES OF OTHER BIOMEDICAL FACTORS

Gastrointestinal Abnormalities

Horvath et al. (1999) reported high rates of reflux esophagitis, chronic gastritis, and chronic duodenitis in 36 children with autism. Unrecognized gastrointestinal disorders were considered as a contributing factor to the behavioral problems of nonverbal autistic patients. Finegold et al. (2002) reported that the number of clostridal species found in the stool in children with late-onset (regressive) autism was greater than that in the stools of control children and suggested such a finding may provide insights into the nature of autism. Black, Kaye, and Jick, (2002) reported that no evidence was found that 96 children with autism were more likely than 449 children without autism to have had definite gastrointestinal disorders at any time before their diagnosis of autism.

Abnormal Intestinal Permeability

An altered intestinal permeability was found in 43% of 21 autistic patients. It was speculated that an altered intestinal permeability could represent a possible mechanism for the increased passage through the gut mucosa of peptides derived from food with subsequent behavioral abnormalities in these patients (D'Eufemia et al., 1996).

Food Allergy

Lucarelli et al. (1995) found high levels of IgA antigen-specific antibodies for casein, lactalbumin and β-lactoglobulin and IgG and IgM for casein in 36 autistic patients. They speculated that food allergy might cause autism.

Xenobiotic Influences

Edelson and Cantor (1998) investigated 20 children with autism and found that 100% of the cases had liver detoxication profiles outside of normal, and that 16 of 18 subjects showed evidence of levels of toxic chemicals exceeding adult maximum tolerance. They proposed that the interaction of xenobiotic toxins with immune dysfunction and continuous or progressive

endogenous toxicity presented in these children caused the development of their autism.

Summary of Other Biological Factors

These hypotheses are intriguing but were based on very small sample sizes. To gain support of these hypotheses, more studies are needed.

CONCLUSION

Since Kanner's (1943) case report of autism, empirical research has convincingly shown that neurobiological factors are of critical importance in the causation of autism. Support for this view comes from studies originating from a variety of disciplines, ranging from neuropathology to genetics. Several important neurobiological findings have been demonstrated, though no abnormalities have been found to be specific for the disorder. Furthermore, the replicability of the findings has not been high. At present, the etiological implications of these neurobiological findings are not clear, nor is it clear whether some of the abnormalities reflect chance associations without any etiological significance for autism. Although some of the inconsistencies are due to methodological shortcomings, they also reflect that autism is a heterogeneous neurodevelopmental disorder with several distinct subtypes. If this is the case, it is anticipated that future studies will determine a range of biological etiologies for the subgroups constituting autistic disorder.

Hence, future research in autism should continue to emphasize the further subclassification of autism. Such an approach will enable investigators to select more homogeneous groups of individuals for future neurobiological research. From this approach, more consistent results could be expected from various independent research groups to further clarify the role of the various factors that contribute to autism.

On the other hand, many different brain deficits (pathologies and impairments) have been proposed as causes for autism. This is mainly due to different emphases of clinical manifestations and etiological theories of the researchers in the field of autism. For example, many researchers emphasize the importance of impaired reciprocal social interaction in autism and have offered different etiological theories, including impaired speech and language development (Rutter, 1974), theory of mind (Baron-Cohen, Leslie, & Frith, 1985), executive function deficits (Ozonoff, Pennington, & Rogers, 1991), memory function deficit (Bauman & Kemper, 1994), and impairment in shifting attention (Courchesne et al., 1994). Today, it is clear that autism is a very complex neurobiological disorder. However,

neurobiological investigators in the field of autism have behaved like the blind scientists who are eager to tell the world about the part of the elephant they have found, although their stories may not tally. Future research direction should also emphasize the collaboration and integration across a range of neurobiological disciplines. If someday the mutant genes responsible for autism are identified by the geneticists in a subgroup of individuals with autism, the mechanisms operating by the mutant genes that in turn cause autism can be studied by neuroscientists specializing in neurochemistry and receptor functions. With further understanding of the gene-induced abnormal neurobiological processes, behavioral neurologists would be able to link the neurobiological findings to the underlying clinical symptoms or behaviors to further elucidate the developmental processes of autism. With the advanced understanding of the neurobiological mechanisms of autism, more effective neurobiological treatments, including both medication and nonmedication interventions, can be developed. Moreover, with better understanding of the mutant genes responsible for autism, we can expect significant advances in learning and practicing how to prevent the development of autism in our children.

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Chapter 3

Past, Present, and Emerging Directions in Education

V. Mark Durand
University of South Florida, St. Petersburg

INTRODUCTION

It has been over 60 years since Leo Kanner first described children with autism. This book portrays some of the accomplishments made in the intervening years that have led to increased understanding and assistance for these individuals and their families. As the reader will see, we have come a long way from the initial descriptions made by Dr. Kanner in 1943. In this chapter, I outline some of those areas that appear to hold promise for moving the field of autism still further ahead in the years to come.

It is important to recognize that attempting to identify significant emerging trends is complicated by the rapid pace of research in the field of autism at this time. What is an emerging area today may be an established fact or an abandoned approach tomorrow. However, several positive trends appear clear. This paper attempts to highlight these trends and put them in their appropriate context with regard to where we have been and where we are today.

Before we begin a close examination of the specific trends, it is possible to make a generalization about the promising research themes in the field. Specifically, researchers who have typically examined the basic processes underlying the deficits seen in autism and those researchers who have tackled these deficits in order to improve the skills of persons with autism appear to be closer than ever in their approaches. Knowledge of basic processes such

as socialization, emotion, and communication is informing remediation efforts, and clinical concerns are in turn informing basic research. This is an extremely important development in the autism field, and one that holds the promise of fruitful collaborations. Outlined next are several of the more significant developments that appear to hold the promise of improving our efforts at educating children with autism.

SOCIALIZATION

Disruption in the development of social relationships is a distinctive feature of autism (*DSM-IV-TR*, American Psychiatric Association [APA], 2000). In fact, what is most striking to a first-time observer is that many people with autism show few outward signs of any differences. It is only when social contact is attempted or when unusual behaviors surface that those unfamiliar with the person recognize something out of the ordinary. For many with autism, the problems they experience with social interactions may be more *qualitative* than *quantitative.* For example, children with autism may have about the same rate of exposure to others as do typically developing children, but the way they make contact is unusual. Although they do not make eye contact and smile at their mothers like children without autism, they still recognize the difference between their mothers and strangers and prefer to be near their mothers in stressful situations (Dissanayake & Crossley, 1996; Sigman & Ungerer, 1984). For example, they will sit near their mothers rather than sit near strangers after being left alone for a short period of time. This research suggests that people with autism are not totally unaware of others, as we once thought; however, for some reason that we do not yet fully understand, they may not enjoy meaningful relationships with others or have the ability to develop them.

Contemporary research looking at teaching socialization skills most often focuses on *how* to teach these skills. Some of these studies examine agents of change (e.g., using peers vs. adults), the context for teaching (e.g., instructional settings vs. play settings), as well as specific teaching approaches (e.g., discrete trial vs. incidental teaching) (Hwang & Hughes, 2000; Rogers, 2000). These are important areas of research because they help focus attention on the fact that children with autism do not learn meaningful socialization skills without intensive and thoughtful intervention. For example, just placing children with autism in the company of typically developing children does not result in the development of useful social skills. However, this begs the question, "Which social skills should we teach?" Does it make a difference in our outcomes which skills are the targets for intervention? Unfortunately, the nature of the specific skills to be taught to these children

receives less attention than do the actual educational techniques themselves (National Research Council, 2001).

Research on the early development of social responses among children with autism may prove useful in specifying important skills to target for these children. *Social orienting*, for example, is an area of study that holds particular promise. Studies of very young children show that children later diagnosed with autism display marked differences from typically developing children, as well as children with mental retardation, in their attention to social versus nonsocial cues. Looking at videotapes of first-birthday parties, some researchers have observed that 12-month-olds with autism fail to orient to social cues such as looking at others or responding to their name (Osterling & Dawson, 1994; Osterling, Dawson, & Munson, 2002). At first glance these deficits sometimes present themselves as perhaps a sensory difficulty (e.g., hearing). However, these children do not show the same difficulty with nonsocial cues. This important problem in socialization may help to explain another core social deficit among children with autism—a failure to engage in *joint attention.* Joint attention involves a series of interactions that young children perform to engage another person in some object or activity of interest. Making eye contact with a parent, looking at a favorite toy, then looking back at the parent with a smile would be an instance of joint attention and is an example of a nonverbal means of sharing a pleasurable experience with someone else. Children with autism as a group tend to do less well on tests of joint attention than do other groups of children (Leekam, Lopez, & Moore, 2000; Travis, Sigman, & Ruskin, 2001).

What this research suggests is that the failure of many children with autism to make eye contact with others is not just an isolated skill deficit in need of remediation. Rather, the implication of this work is that there is something about social stimuli that these children seem to ignore or avoid early in their development, which may in turn interrupt beginning social development. One logical response to this aspect to social development would be to actively encourage these children to attend to social stimuli at a very early age. Readers will note immediately that many behavioral programs initiate training by teaching eye contact (e.g., Lovaas, 1977). The phrase "Look at me" along with any required prompting is a typical discriminative stimulus that signals the beginning of a learning trial.

Importantly, the findings from the social orienting and joint attention literature point out the need to focus more generally on the broader set of skills needed to encourage children to engage others. For example, Zercher, Hunt, Schuler, and Webster (2001) examined the effects of participation in an integrated play group on the social orientation of two boys with autism. Three typically developing girls engaged the boys in their play activities as coached by adults, and the researchers observed improvements in shared attention as well as in symbolic play and verbal language. These findings are

encouraging and suggest an approach to early intervention for socialization. Educational efforts will be able to take advantage of the refinements in our knowledge of the symptoms of autism (e.g., eye contact vs. joint attention) and perhaps create changes that lead to generalized improvements in skills.

EMOTIONAL PROCESSING

The previous discussion, as well as most of the literature in this area, has at its core an unspoken assumption—that difficulties with socialization in areas such as social orienting and joint attention are skill deficits. For example, it is often assumed that children with autism do not display shared attention because they lack the ability. From this assumption, it follows then that if we simply teach the skills, these children will perform them. However, what if children do not learn certain skills because they lack the motivation to engage in them? These children may be capable of the basic skills necessary for socialization, but may not perform these skills because they are not interested in social interaction. This issue may be at the heart of future trends in education because it directs our focus from just teaching skills to addressing emotional processing of information by children with autism.

Emotional processing is generally believed to be made up of three components: behavior, physiology, and cognition (Durand & Barlow, 2003). For example, to say someone experiences fear would involve fearful behavior (e.g., running away), fearful physiology (e.g., sweating and rapid heartbeat), and fearful cognition (e.g., thoughts of being hurt). Important for this discussion, the social–communicative efforts of children with autism are often hampered by the presence of inappropriate emotional responses. For instance, some children can say the right words to a peer or an adult, but the *way* it is said or the facial expression used may not match the content of the message (e.g., saying "I'm sorry" with a smile on your face). This lack of concordance between behavior and the presumed emotional experience of the child characterizes many of our efforts to teach social–communicative skills to persons with autism.

Reciprocal emotional responding is important for communication, and some research suggests that this skill may be difficult for many children with autism. Sigman, Kasari, Kwon, and Yirmiya (1992) have examined the emotional expressiveness of children with autism and children with mental retardation in order to evaluate diagnostic differences as well as potential contributory factors to their learning difficulties (Capps, Kasari, Yirmiya, & Sigman, 1993; Sigman et al. 1989; Yirmiya, Kasari, Sigman, & Mundy, 1989). Compared to other children, children with autism look at adults less and are more engaged in other activities when a nearby adult shows signs of being hurt (Sigman et al. 1989). Other research has begun to examine how well people

with disabilities can recognize the facial expressions of emotion in others (McAlpine, Singh, Kendall, & Ellis, 1992).

Another related area of research is in a phenomenon known as *theory of mind.* When typically developing individuals encounter another person, they usually engage in a form of mind reading. We try to infer from someone's behavior what he or she might be experiencing. For example, seeing one person talking to a group and then observing the group laughing together might be interpreted as the speaker telling a humorous story or joke, and the rest of the group enjoying it together. Our ability to infer intention and emotion from behavior is essential for making close connections with other people. However, we know that many people with autism lack a theory of mind and do not make this behavior–emotion connection (Baron-Cohen, 1995). This has led some to attempt to teach children and adults who have autism to *read the minds* of other people in order to improve their social–communicative abilities. For example, Hadwin, Baron-Cohen, Howlin, and Hill (1997) taught children with autism to interpret the behaviors of other children in a variety of situations. The researchers hypothesized that if the children could *understand* intentions then this would lead to improvement in skills such as engaging in conversations. However, despite evidence that they could increase this ability to infer intentions, this did not result in improvements in other skills (Hadwin et al. 1997).

The evidence that a lack of theory of mind is unique to autism has come under close scrutiny. It appears that persons with other disabilities such as mental retardation, deafness, blindness, and language impairments may also have deficits in this area (Tager-Flusberg, 2001). Important for our discussion, however, is the nature of this deficit. Do children and adults not *read minds* because they cannot or will not? Is the primary deficit a lack of social motivation (i.e., not being interested in other people and their responses), and does this in turn lead to the failure to engage in certain skills such as mind reading? Much of the theory of mind research is based on the premise that this is primarily a cognitive deficit. People with autism are believed not to infer emotions in other people because of a cognitive processing deficit. This suggests that if the skill can be taught—for example, teaching a person that when others raise their eyebrows and tears come down their faces, that they are unhappy—then the person with autism will cognitively *understand* emotion and will be able to use this new skill to improve other social–communicative skills.

Recall that emotional processing involves three components: behavior, physiology, and cognition. The implication here is that without the physiological component of emotional processing—not feeling the emotions of others—it may not be possible to truly integrate the phenomenon of emotion and thus use it to relate better to others. We have focused on the behavior and the cognition associated with emotional processing, but we have

yet to address the physiological component. In other words, how do we get persons with autism to feel the emotions of others? What this would involve is a form of *empathy training*—teaching people with autism to match their feelings with the feelings of others. We relate to other people who are upset, for example, because we become upset as well. This phenomenon is called *emotion contagion* and would be one approach to making this connection. Emotional contagion is "the tendency to 'catch' (experience or express) another person's emotions (his or her emotional appraisals, subjective feelings, expressions, patterned physiological processes, action tendencies, and instrumental behaviors)" (Hatfield, Cacioppo, & Rapson, 1992, p. 153). An important advance would be the ability to produce this phenomenon in persons with autism.

This type of research is valuable in pointing to potential obstacles for children with autism in learning important social skills. Building friendships, for example, is seen as an important goal for people with autism and other developmental disorders (Hurley-Geffner, 1995). Activities such as sharing, cooperative play, giving and accepting compliments, and responding to initiations by peers are just some of the skills needed to establish friendships among children. However, the research on emotional processing suggests that children with autism may need assistance in developing the foundation emotion-related skills to successfully traverse the labyrinth of activities needed to build a friendship. Structured activities such as using pictures (e.g., *social stories*; Gray & White, 2002) are being explored as one possible format for this type of teaching. An important future direction will be to explore techniques for teaching people with autism to recognize and respond appropriately in situations with significant emotional content (Gena, Krantz, McClannahan, & Poulson, 1996).

COMMUNICATION

One area of education that is extremely important for students with autism is the domain of language and communication. Both verbal and nonverbal communication abilities are core deficits among these individuals and serve as the subject for significant amounts of research (Howlin, 2003; National Research Council, 2001). Language deficits can be seen as pivotal to the problems experienced by persons with autism because they are correlated with an unfavorable prognosis and may contribute to problems in socialization. The remediation of language deficits, therefore, has received much attention.

There is a voluminous literature on language training for students with autism (see, for example, Goldstein, 2002). Unfortunately, this apparent success in teaching language has not been achieved in all children. Some

children make limited progress despite intensive behavioral intervention (National Research Council, 2001). For them, work has focused on alternatives to vocal speech (Light, Beukelman, & Reichle, 2003). Although most of the early controlled research on these alternatives has been with the use of sign language (Carr, 1982), there are problems of generalization. Specifically, community members are often unfamiliar with sign language and therefore cannot successfully interact with these students. In addition, the signs made by many students are frequently idiosyncratic and are difficult to understand by even experienced teachers (Durand, 1990).

One alternative to both spoken and signed speech is the use of augmentative communication systems (Baumgart, Johnson, & Helmstetter, 1990; Light et al., 2003). These systems are formal or informal strategies that assist communication efforts instead of or in addition to spoken speech. These strategies have included using communication boards that require students to point to pictures (Mirenda, 1985; Rotholz, Berkowitz, & Burberry, 1989), vocal output devices that use synthesized speech (Mirenda & Beukelman, 1987), and a variety of other adaptations (Johnson, Baumgart, Helmstetter, & Curry, 1996).

In addition to occasionally failing to teach speech to children, behavioral procedures have been criticized for not producing language that is used by children to communicate spontaneously with others. For example, a child might be taught to respond to the phrase "What do you want?" with the word, sign, or by pointing to a picture of "soda." However, he or she would probably not spontaneously and appropriately request soda without the prompt. One trend in language training research addresses this issue of language use. More than 20 years ago, Hart and Risley (1980) developed a set of "incidental teaching" procedures that have helped language-delayed children to communicate with others more spontaneously. Incidental teaching occurs in the natural context (e.g., in the kitchen or at a shopping mall) and with a variety of relevant persons (e.g., teacher, parents, and peers). Teaching episodes are initiated by the child and are encouraged through reinforcers related to the topic of discussion (i.e., "natural" reinforcers). Important work applies these procedures to children with autism, with encouraging results. Reviews of this approach suggest that using incidental teaching for new skills may be as successful as using discrete trial procedures but may have the additional benefit of improving functional use of the skills and may be preferred by family members (Delprato, 2001). As with other areas of instruction, efforts to teach communication will tend to move away from using simulated settings, tasks, and consequences toward using those aspects of the prevailing environment that are relevant to the skills being taught.

There are parallels between the literature on communication skills training and the literature on socialization training. Much of the focus in this area has been on how to teach these skills rather than on what skills to

teach. Fortunately, there are several interesting studies that recognize the importance of the types of skills to teach. For example, Buffington, Krantz, McClannahan, and Poulson (1998) looked at teaching gestural skills in addition to verbal communication. The goal was to teach children with autism to combine gestural and verbal responses to answer questions. For example, when asked a question such as "Who wants to ___?" the children were taught to raise their hands and say, "I do." This combination of verbal and gestural responses more closely approximates the responses of typically developing children in these situations.

In addition to the *form* of communication, researchers are also beginning to explore the teaching of different *functions* of communication. Historically, most studies focused on teaching requests (e.g., "I want a cookie" "Soda, please"). This choice of responses was not accidental. Assisting children to get their needs known and met is an important goal. Additionally, the consequences for correct responding are something the child wants. These requests (or "mands") typically are maintained by nonsocial reinforcers (e.g., they receive the requested cookies or soda, which is what maintains the communicative responses). However, not all communication occurs because something tangible is obtained as a consequence. For example, saying hello to a friend in the school hallway or pointing out something of interest to a classmate is not usually followed by some object or activity. In fact, typically developing children will make such responses just to make social contact or to maintain such contact. Because such social consequences may not be reinforcing for many children with autism, it is not surprising that these skills are more difficult to teach.

Again, there are some in the field who are attempting to teach these more challenging communication skills. In one study, Koegel and colleagues (Koegel, Camarata, Valdez-Menchaca, & Koegel, 1998) taught three children with autism to ask questions by placing favorite items in a bag and prompting the children. When the child said "What's that?" he or she received the item in the bag. By using delayed prompts and intermittent reinforcement (sometimes placing nondesired objects in the bag), students generalized this question-asking skill. The goal here is to pair nonsocial motivation with adult and child attention into these typically socially motivated interactions until the child responds to the social reinforcers alone. The continuing challenge for the field is to teach skills that are typically maintained by their social consequences to individuals for whom these consequences are not similarly motivating. One approach, as just illustrated, is to pair reinforcing events (e.g., a favorite toy) with nonreinforcing events (e.g., indications of approval from others) until secondary reinforcing properties become associated with the social cues. This way, individuals with autism would be motivated to continue to use skills that usually only have outcomes that are less desired (e.g., social outcomes).

INCLUSION

Perhaps no other trend in education will have more far-reaching effects on daily practice than the inclusion of children with autism into the academic and social lives of their same-age peers (Peck, Odom, & Bricker, 1993). This effort rivals the widespread effects on education observed after the passage of Public Law 94-142. The move to include these children into regular classrooms has proceeded slowly but steadily over the past decade. Writers in the early 1980s called for moving children with disabilities out of segregated schools into special classes in the regular school (e.g., Brown et al., 1983). This movement has followed its logical progression by recommending that all students, regardless of disability, be placed with same-age peers in regular schools (e.g., Brown, Long, Udvari-Solner, Davis, 1989; Long, Udvari-Solner, Schwatrz, et al. 1989). Although support for inclusion predates the 1980s, it has only been recently that this idea has been embraced by large numbers of parents and professionals (for a more complete discussion of the history of integration, readers should refer to Lipsky & Gartner, 1997; and Nisbet & Hagner, 2000).

Although the concept of inclusion for children with autism has its critics (see Kaufman & Hallahan, 1995, and Mesibov & Shea, 1996, for example), the move toward full inclusion for these children will provoke fundamental changes in all aspects of educational activity. In assessment, for example, the emphasis is changing from using educational assessment as primarily a placement activity because placement is being based largely on chronological age. In addition, assessing most skills will benefit from the availability of direct comparisons with typical peers. For example, determining what is appropriate social behavior will be easier with more accessible, socially competent models (Werts, Caldwell, & Wolery, 1996).

An additional trend motivated by the full inclusion of children will be a change in the content of educational plans. The *how* and *what* of teaching should be influenced directly by the students sharing their classroom. For instance, using restrictive procedures for modifying challenging behavior looks inappropriate given most community standards. Also, the move away from teaching readiness skills that is already apparent should be helped by inclusion efforts. The inappropriateness of teaching nonfunctional skills becomes even more obvious when it is carried out next to the more functional activities of their typically developing peers.

One of the most obvious changes that should take place with full inclusion is a change in expectations. It is inevitable that educators who teach in classrooms with only students who have disabilities will have expectations for them that differ from the norm. Changes in expectations in inclusive settings will range from issues of appearance (e.g., finding it unacceptable for a student to come to school with an unbuttoned shirt or with dirty hair)

to expectations about interacting with peers (e.g., not allowing students to spend long periods of time alone). Clearly, just placing students in inclusive settings without support will not result in meaningful results. However, model programs have been developed internationally that successfully include students with a broad range of abilities (e.g., Harris, Handleman, Kristoff, Bass, & Gordon, 1990; Roeyers, 1996; Zanolli, Gaggett, & Adams, 1996).

Much of what some would consider as a *treatment* for the symptoms of autism is actually an extension of what occurs for most children at school. However, in addition to focusing on the traditional academic skills such as reading, writing, and mathematics, the goal for children with autism shifts to many of the nonspecific effects of school. For example, friendship making is not typically a subject taught in a class but occurs among children through their everyday contact. On the other hand, for children with autism this does not develop in a typical fashion and should be a major area of concern for any educational plan. Some efforts are underway to aid educators in designing programs that meet the very specific and sometimes unique needs of children with autism. In New York, for example, autism program quality indicators have been developed to assist programs in their efforts to design successful interventions in schools (Crimmins, Durand, Kaufman, & Everett, 2001).

EARLY INTERVENTION

One of the most exciting trends in work with children with autism was touched off by a ground-breaking study by Ivar Lovaas (1987). Lovaas and his colleagues at UCLA reported on their early-intervention efforts with very young children (Lovaas, 1987). One group received intensive behavioral treatment for their communication and social skills problems for 40 hours or more per week. A second group of these very young (under 3½ years of age) children with autism received less intensive behavioral treatment, averaging 10 hours or less of one-on-one treatment per week.

After more than 2 years of this treatment, the children were followed up to assess their progress as they entered school. It was reported that 47% of the group receiving the intensive treatment (40 or more hours per week) achieved normal intellectual and educational functioning, doing well in regular first-grade classes. In contrast, none of the children in the less intensive treatment group achieved this level of improvement. The 47% who improved so dramatically tended to be those children with a higher mental age at the start of treatment. A more recent follow-up of these children who were then 11 years old indicated that these improvements were long-lasting (McEachin, Smith, & Lovaas, 1993). This series of studies has created

considerable interest as well as controversy in the field, with some critics questioning the study on practical (e.g., too expensive and time consuming to provide one-on-one therapy for 40 hours per week) as well as experimental (e.g., no proper control group) grounds. Despite the controversy, however, the results suggest a more optimistic attitude toward early intervention for children with this disorder (Rogers, 1996).

A number of studies currently are available that replicate these positive effects of early intervention for children with autism (Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Fenske, Zalenski, Krantz, & McClannahan, 1985; Harris et al. 1990; Hoyson, Jamieson, & Strain, 1984; Rogers & DiLalla, 1991; Rogers & Lewis, 1989; Rogers, Lewis, & Reis, 1987). There are, however, several questions that remain with regard to early-intervention efforts. For example, will *all* children with autism benefit significantly from such efforts? Research thus far suggests that young children with autism that do not also exhibit severe cognitive impairments (significant mental retardation) are more likely to make significant gains (Rogers, 1996). Also, how much intervention effort is required to observe these positive effects? Intensive behavioral intervention less than the 40 hours per week used by the Lovaas group (15 hours per week or more) seems sufficient to demonstrate impressive effects (e.g., Anderson et al. 1987; Hoyson et al. 1984).

Several of the studies use class placement as an outcome indicator for these programs. In other words, if the child is in a regular class at follow-up, this is viewed as one positive outcome of the early intervention program (Lovaas, 1987). One question that needs to be assessed in these outcome studies is the possible role of inclusion as both a *process variable* in successful early-intervention programs as well as an *outcome variable.* Put another way, does placement in a typical class promote positive social outcomes in these students? There is some research to suggest, for example, that at least some children with autism can benefit directly from their interactions with their peers (Roeyers, 1996). This may be especially true for the children who already have some language skills, the type of child who benefited most in the Lovaas study. Being exposed to appropriate models may be an important aspect of treatment in these early-intervention programs.

Additionally, differing expectations by regular education versus special education teachers may also serve to assist with the success of the students in integrated settings. Expecting more of children, which may occur in regular education settings, can affect how a child behaves (Stoneman, 1993). This may be especially important for the more subtle social skills that children with autism often lack. Their teachers and the typical peers may be best able to provide explicit and implicit feedback to these children on their reactions to others.

We have relatively little research on the interactive effects of intensive behavioral intervention and integrated placements on the behavior of children

with autism. The focus of most of the attention on these programs has been solely on the structured educational aspects of the programs. However, engaging children in intensive behavioral intervention exclusively in segregated settings may not be sufficient to create the type of long-term positive results observed in the model programs. A future direction for researchers should be in widening the focus to include other unprogrammed aspects of these programs.

CURRICULUM CONTENT

Again, intervention research with students displaying autism has traditionally focused on *how* students are taught, sometimes at the expense of information about *what* these students should be taught. For example, we know a great deal about how to break skills down into individual components (task analysis) and how to shape successive approximations. However, what are the best skills to teach using this technology? Should we teach students the prerequisites to important tasks (e.g., prevocational, preacademic tasks), or should we begin to teach approximations to useful skills right away? Do we need to get students ready to learn language, or should we use augmentative communication strategies to allow them to interact with others more quickly?

These questions are at the forefront of education for children with autism and other developmental disabilities. And to date, there is no empirical answer to these questions. No one has yet answered the question as to whether children need to be "readied" for meaningful education. In the absence of this information, the current trend is to assume that students can learn meaningful skills *while they are being taught meaningful skills.* In other words, rather than teaching isolated skills to prepare a student for an activity, teachers are introducing the real activity in real settings and teaching necessary approximations. An example illustrates these two contrasting approaches.

A teacher in one school was describing to me a program to teach a student how to independently get on and off the school bus. She told me that they had stairs made up that were like the steps in the bus, and that each day they would practice walking up and down the stairs. I commented that the bus had the hand railing on the right side, but their stairs had the railing on the left side. I also noticed that the first step on the bus was much higher than the one in school and that the small opening in the bus appeared to be anxiety provoking for the student. All of these differences could make the transition from the school stairs to the real bus more difficult. The teacher said that they could get the stairs modified to more closely approximate those of the bus. I then pointed out that they already had stairs that would be

perfect—those on the bus. Why not teach the student to climb the bus steps in the minutes that were available at the end of the day while students were waiting to be picked up? Not only were the stairs exactly like those that the teacher wanted the student to master, but also, as a reward, the student could go home! One solution to problems of generalization and maintenance is to teach useful skills in the setting where you want the student to use the skill (e.g., on the bus) and with the people who will be present there (e.g., the bus driver).

KEEPING THE "FUN" IN FUNCTIONAL

There is a clear and obvious trend away from just teaching prerequisite skills in analog-type settings to teaching useful or functional skills in real settings. As this emphasis continues, a new problem will emerge in our curricula. It is appropriate that we spend a great deal of time teaching our students skills that will assist them in becoming more independent. Yet, at the same time, we must balance these efforts with activities that are not only functional but also fun. This is not a concern that is specific to teaching functional skills. For example, recent research indicates that the outcomes of standardized tests can be improved significantly in children with autism by improving their motivation and interest in the tasks (Koegel, Koegel, & Smith, 1997). An example may illustrate this point best.

Some mornings it was my responsibility to awaken my young son at 6:30 a.m. Not being a "morning person," I would rather walk over hot coals than wake up that early in the morning. At that age, my son must have sensed this attitude in me, because my mornings with him were usually disastrous. He typically fought getting out of bed, resisted getting dressed, and complained when washing. In contrast, my wife's mornings with our son were usually quite pleasant. One clue to the differences in our early wake-up routine came one morning when I heard my wife telling my son knock-knock jokes. They teased each other for about 5 minutes before she announced, "Ok, time to get dressed," in a cheery tone of voice. With that vignette in mind, the next morning I went into my son's room saying in a soft sing-song voice, "Who's the sleepiest person in the house—I am." A little smirk came across his face, and after a few repetitions, he was answering, "No, I am" with a big smile. The rest of the morning was both productive (he got off to school on time) and fun.

Too often, many good teachers are pressured into teaching so many useful skills in such a short amount of time that they forget that the *process* should be enjoyable. Parents, too, complain that efforts to make them better parent trainers sometimes interfere with the more enjoyable aspects of being a family (Singer, Powers, & Olson, 1996). The challenge for our field will be

to design environments that teach functional skills within a context that encourages play, humor, and friendship. It will be important to keep the *fun* in functional.

CHALLENGING BEHAVIOR

An ongoing concern faced by family and friends of children with autism is the too-frequent presence of challenging behaviors, such as aggression and self-injurious behavior. These behaviors often represent one of the major obstacles for children to fully participate in meaningful educational activities. Fortunately, our knowledge of the origins of these behaviors has increased over the past few years along with our ability to respond to these behaviors in a positive, constructive way (Durand, 1990; Horner et al., 1990; Meyer & Evans, 1989). As a result of this expansion of knowledge, work on interventions with persons exhibiting severe challenging behavior has increased in areas such as environmental and curricular changes (Dunlap, Kern-Dunlap, Clarke, & Robbins, 1991; Evans & Meyer, 1985; Meyer & Evans, 1989) and teaching specific alternative skills (Durand, 1990). This expansion of the range of intervention targets—from interventions for single behaviors to comprehensive and multimodal intervention across a range of lifestyle change—has been referred to as *positive behavioral supports* (Horner et al. 1990). The federal government has codified these approaches through the reauthorization in 1997 of the Individuals with Disabilities Education Act (IDEA) and mandates the use of positive behavioral supports for students with challenging behavior. A review of all of the research on this approach to treatment is beyond the scope of this paper; therefore, we focus on a few important aspects.

One intervention that has received significant empirical support in reducing the frequency of challenging behavior involves teaching functionally equivalent responses, such as communication, which serve the same function as the student's problem behavior (e.g., functional communication training [FCT]; Carr & Durand, 1985). With growing evidence of the value of this intervention approach in reducing a variety of problem behaviors, important new research is evaluating how FCT compares with other interventions. Hanley, Piazza, Fisher, Contrucci, and Maglieri (1997) for example, compared the effectiveness of FCT with noncontingent reinforcement (NCR) on the multiple behavior problems of two children. They found that both interventions initially reduced problem behaviors, but that the participants demonstrated a preference for FCT. This advantage—preference by consumers—should not be underestimated. Too often we design interventions that are in some way not acceptable either to the persons implementing the procedure or to the person who is the target of the intervention. Often this leads to problems with implementation and in turn

can contribute to difficulties with generalization and maintenance. Future research will focus on interventions that are acceptable to the consumers—in this case, children and youth with autism. This concern is consistent with efforts to increase *self-determination* among these individuals (Wehmeyer & Bolding, 1999; Wehmeyer & Metzler, 1995).

An important aspect of an intervention—its usefulness outside of specially designed settings—is an essential advance that will need to be addressed in the coming years. Too often for people with autism, interventions are implemented that cannot be used in regular education classrooms or in typical community settings. A handful of studies may signal the beginning of important efforts to focus on this issue. Durand and Carr (1992), for example, compared the effectiveness of FCT with time out from positive reinforcement for the attention-maintained behavior problems in two groups of children. An initial finding was that both interventions were successful in reducing these problem behaviors. However, further analysis showed that when the students were in the presence of a teacher who was unaware of the different interventions that had been used, only students who had received FCT continued to display low levels of problem behavior. These students continued to request (and receive) attention, which appeared to account for the effectiveness of this intervention with untrained individuals.

One study more directly addressed the ability of FCT to be successful in typical community settings. Durand (1999) evaluated the effectiveness of FCT as an intervention for the problem behavior exhibited by five students with severe disabilities both in school and in the community. Following an assessment of the function of their problem behavior, the students were taught to use assistive communication devices in school to request the objects and activities that presumably were maintaining their behavior. The results indicated that not only did the students use their devices successfully, but also the intervention reduced their problem behavior outside of school and with untrained community members.

These findings take on added importance when one considers that an increasing number of individuals who engage in severe behavior problems are living and working in community settings. It is obvious that people including bus drivers, fast-food restaurant workers, or store clerks will not be trained to implement sophisticated behavioral programs such as time out from positive reinforcement as a consequence for problem behavior or noncontingent reinforcement to decrease these behaviors. Yet, these same individuals may be able to understand simple requests for attention or assistance and therefore be able to respond in a limited way to the communication of people with intellectual disabilities. The challenge becomes one of teaching people with behavior problems ways of communicating that will be understood even by people who do not have training in the area of communication difficulties or autism.

In addition to expanding our arsenal for treating severe behavior problems, one issue remains unresolved. Can we prevent behavior problems from developing among such a large number of children and youth with autism? This will be an important area of study in the coming years, and will require research in a number of fields. Some preliminary research on the development of challenging behavior among young children may open up a new avenue for preventing these problems. A 3-year longitudinal prospective study examined factors that might contribute to later behavior problems in young children (Durand, 2001). Following children from age 3 to age 6, a number of factors were measured to assess their role in predicting which children would later display more severe behavior problems. Surprisingly, the most significant factor in predicting later behavior problems was not the severity of problems at age 3; nor was it the extent of cognitive or adaptive behavior deficits initially displayed by the children. Rather, the best predictor of which children would have more severe problems 3 years later was a measure of parental pessimism. In other words, parents who had *given up* on their ability to influence their child's behaviors by the time the child was 3 years of age were most likely to have children with more difficult behaviors later in life. This finding was true despite the fact that some of the children with more optimistic parents initially had more severe deficits and behavior problems. It appeared that parental optimism may have served as a protective factor for these children.

If these results are found to be reliable, it may make fundamental changes in the way we work with families of young children. In addition to the traditional approach of providing parent training to families, we may need to identify those parents who are a risk for feeling out of control with respect to their child's future and provide them with additional therapeutic supports to help them feel more empowered. Fortunately, there is important work addressing pessimism and the need for some people to address feelings of being out of control, and this research may be an invaluable addition to our traditional approaches for helping these families (Seligman, 1998).

MEANINGFUL OUTCOMES

A great deal of progress has been made in the education of students with autism. The chapters in this book highlight the tremendous strides made in the last few decades. Yet, despite our progress, it may be useful to reflect on these accomplishments and their impact on the lives of our students. Here the question becomes, "Have these advances resulted in *meaningful* changes in our students?" Finding solutions to this question will prove to be the most difficult challenge facing educators in the next decade.

As described earlier, investigators have succeeded in teaching children to engage in a variety of communicative and social behaviors. Yet,

interpretation of these results should be viewed with caution. What has yet to be demonstrated is that significant others view these behavioral increases as important. In other words, some measure of the social validity (Voeltz & Evans, 1983; Wolf, 1978) of the effects of this training is needed. For example, are nonhandicapped peers more likely to accept children with autism following social skills training? Will they initiate significant contacts outside of the training contexts (e.g., invitations to parties, choosing them on sports teams). This issue is particularly important in light of recent findings that social skills training with these children does not always result in increased acceptance by classmates (Tantam, 2000). Thus, it seems likely that special efforts may be necessary to produce important changes in the social repertoire of children with more severe disabilities, such as those with autism.

One approach to ensuring the social acceptability of our outcomes is appropriate selection of responses as targets for training. For example, hugging may not be appropriate as a first response to teach adolescents who interact with other high school students. Selection of appropriate targets should probably involve persons likely to interact with trainees. These *significant others* may be able to identify the behaviors needed to be accepted by a particular social group. Future research in this area should address the issue of social validity of both the effects and the targets of skills training. This emphasis is necessary in order to demonstrate clinically significant results from efforts to improve these childrens' skills.

SUMMARY

In this chapter, I attempt to identify new directions in educational programming. Trends are observed in a variety of areas that may have a profound impact on the way students with autism are taught in the future. Most importantly, pervasive change will result from the continued communication between researchers in the more basic areas of research (i.e., the nature of the social deficits in autism) and those who design and evaluate intervention strategies. This type of reciprocal relationship should prove to be extremely fruitful and rewarding. With the many advances being made in almost all aspects of intervention, there is room for great optimism in the future of education for students with autism.

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Chapter 4

The Evolving Role, Impact, and Needs of Families

Anton Hecimovic
Montana State University–Billings

Susan Gregory
Montana State University–Billings

INTRODUCTION

Nick recently turned 24. His parents have always dreamed that despite his autism and moderate mental retardation, he would have a full life in his community. Their dream had specific components, including a home in a local neighborhood, regular recreational opportunities, continuing education, and adequate financial support.

Part of Nick's parents' dream for him has been fulfilled. He has his own home in the community, which while small, is his. He has had several opportunities to get jobs in the community. Unfortunately, these have not worked out, often because of his difficulty in adjusting to the various demands of the community work sites. As an alternative, he has had the option of working in an agency serving people with disabilities. Nick spends most of his time sitting at home watching television, at times with a person from an agency who is paid to provide him with supported living assistance. He seldom chooses to go out into the community for anything but essential activities. He is gaining weight, which is jeopardizing his health. Nick and his family, like others who face the challenge of autism, are slowly seeing their dreams turn into nightmares.

Tim is 11 and has severe autism. He and his family recently moved from another state when his mother's employer transferred her. In addition to serious communication problems, Tim has difficulty sleeping through the

night, gets upset easily, and has not yet mastered many self-help skills. Tim's parents, wrestling with the challenge of meeting his needs while also meeting their other children's needs, have requested from the school an extended-day and extended-year school program for him. The school superintendent has stated that such a request is beyond the small school district's capability and responsibility. However, the superintendent has said that the school district would be willing to send Tim to a residential school. Tim's parents want him to remain at home, in the local community. They argue that, in addition to being better for Tim by providing him the needed support to allow him to stay at home and be an active part of their family, their request would actually cost taxpayers less than it would cost to go to the residential school. The superintendent refuses to grant the parents' request. Consequently, Tim's parents have hired an attorney and are beginning the long, arduous, expensive process of fighting to secure what they know is appropriate schooling for their son.

Sarah just celebrated her fourth birthday, complete with balloons, cake, ice cream, and six of her preschool friends. A year ago, Sarah was diagnosed with autism. She exhibits a number of typical characteristics, including language delay, stereotypic behaviors, unresponsiveness to others, and unusual patterns of play. Sarah attends a regular preschool program funded by the school district. She receives swimming lessons at the YWCA. Sarah also attends preschool every day along with other neighborhood children her age. Sarah's parents have resisted placing her in the special "autism preschool," as they call it, stating that their daughter is best served in the programs she would attend if she had no labeled disability. They work with a number of professionals committed to full inclusion of children with autism.

These are three individuals with autism. Each experiences autism in a unique way. Each of these individuals also is a member of a family, a unique and complex system of relationships, experiences, values, and expectations. Nick, Tim, and Sarah share a common diagnosis, autism; however, their life experiences are as different and as individual as any in society.

Children and adults with disabilities like Nick, Tim, and Sarah are the typical focus of special education services, yet their families also require unique attention and support services. This chapter covers some of the issues involved for professionals who have chosen to support Nick, Tim, Sarah, and their families, and thousands of other families experiencing similar situations. This chapter addresses ways for professionals to become aware of, and sensitive to, the needs of families of individuals with autism, including those members of the family whose needs are often forgotten by professionals.

We consider the needs of different family members, and also of the whole family, as an interrelated, interdependent system. A critical determinant

of the family system's support is the nature of the family–professional relationship, and how families view that relationship. It is this relationship, and the sensitivity, skills, and information with which professionals approach the relationship that define how much support families receive from the professionals with whom they will interact, simply because they happen to have a family member who experiences autism.

CHALLENGING THE OLD ASSUMPTIONS ABOUT FAMILIES

Historically, the attitudes and assumptions of professionals in the field of autism have defined the service delivery and support provided to families. Professionals, especially educators, physicians, psychologists, and social workers, assumed roles of authority in working with families of children with autism. The approach to families of children with disabilities until the 1980s was that of the medical model, in which the assumption was that the child's disability had a negative impact on the family (Ferguson, 2002). Bruno Bettelheim's work the *Empty Fortress* (1967) is the classic example of the potential damage that professional opinion can have on families.

Some historical assumptions and misconceptions that were made about families included the following:

1. *The doctor knows best.* Families were expected to listen to the all-knowing professional, without question. Families needed to trust the wisdom of the professional (Lyon & Preis, 1983).
2. *Parents contribute to the child's problem.* Parents were directly blamed for the cause of their child's disability (Berlin, 1973; Bettelheim, 1967; Tinbergen & Tinbergen, 1972).
3. *Parents are unrealistic.* Parents were thought to have unrealistic expectations about their child with autism. Some professionals believed that parents were not willing to accept the "realities" of their child's disability (Cutler, 1981; Stanhope & Bell, 1981).
4. *Parents need professionals to solve problems for them.* A commonly held belief among professionals was that the needs of the child with autism were so great that parents could not be expected to manage the child without extensive professional intervention.
5. *All parents need counseling.* Some professionals believed that with the stress of having a child with autism the parents would need counseling.

Despite there being no scientific evidence to support the view that parents were the cause of their child's autism (Wing, 2001), these negative assumptions hindered productive family–professionals partnerships, and resulted

in labels readily being applied to families, such as overprotective, guilt ridden, unaccepting, uncaring, or noncompliant (Seligman, 1979).

A NEW AND BETTER WAY OF THINKING ABOUT FAMILIES

The past 20 years have seen significant changes in attitudes toward families and their role in the services that are provided to their child. Professional attitudes have been shaped by research, which has refuted the psychogenic theories proposed by Kanner (1949) and Bettelheim (1967).

Ferguson (2002), in a historical review of research on parental reactions to having a child with a disability, points out that researchers no longer focus exclusively on the negative impact on the family with a child with a disability. He points out that more current research reflects a growing number of parents who report the positive effects on their family because of having a child with a disability.

Parents and other family members are recognized as essential partners in the process of providing services to their child. This change is reflected in legislation such as the Individuals with Disabilities Education Act (IDEA). This provides the legal basis to authorize family participation in the educational decision-making process. The Individualized Family Support Plan (IFSP) for infants and toddlers focuses on the needs of the family, not just on those of the infant or toddler. The foundation of early childhood intervention services is to see the child within the context of the family. Similarly, the Individualized Education Plan (IEP) process requires that families be active participants.

The new way of thinking about families is characterized by the following points:

1. *Children grow best in families.* Children with autism need to be offered the opportunity to live in a family structure and to enjoy a rich array of interaction and activity grounded in the family's culture and beliefs.
2. *Family members are interdependent.* Families are best viewed as a system (Turnbull & Turnbull, 2001). The members of the family interact reciprocally and are mutually interdependent. As a result, professionals need to understand, appreciate, and work with the entire family system to provide meaningful support.
3. *Parents are the best judges of their children's needs.* Parents, not professionals, know their children better than anyone else and are in the best position to judge what services and supports are needed by the child (Wing, 2001). Parents need to be supported in their efforts to secure needed services and supports.

4. *The family is the best advocate.* The family is the best long-term advocate for the child with autism. Not only is the family relationship a long-lasting one, but also family members are in the position of putting the autistic individual's needs and well-being before the potentially conflicting priorities of other advocates.
5. *Families want involvement.* Families want and need to be actively involved in all aspects of the child's educational program. Legislation has given parents the right to be involved throughout the decision-making process for their child's educational career.
6. *Parents should question professionals.* When parents are given confusing and conflicting information about their children with autism, parents must question the information. Assertive parenting suggests good advocacy.
7. *Autism need not be negative.* The child with autism can add to the family system and enhance the family unit. Parents of children with disabilities have reported benefits to their family from having a child with a disability (Singer, 2002; Taunt & Hastings, 2002).
8. *Concern is for the long term.* Parents and professionals share concern for the long-term functioning of the child with autism. There are many real day-to-day concerns, but the future and longer term should be kept in the forefront.

FAMILY-CENTERED SUPPORT

The term *family centered* has been the foundation of services to young children with disabilities for some time (Dunst, 2002; Dunst, Johanson, Trivette, & Hamby, 1991). It is an approach that is consistent with supporting families of children with autism—to let *them* determine and meet their own needs with the assistance of supporting professionals.

Although some family-orientated services and programs might be seen as *professional centered, family allied, family focused,* or *family centered,* the latter concept embodies a unique combination of principles and practices that should make them the goal of all professionals working with families who have a member with autism. According to Dunst and his colleagues (1991), true family-centered models of services for families can be recognized because they have the following characteristics:

> Practices are consumer driven; that is, families' needs and desires determine all aspects of service delivery and resource provision. Professionals are seen as agents and instruments of families, and intervene in ways that maximally promote family decision making, capabilities, and competencies. Intervention practices are almost entirely strength and competency based, and the provision

> of resources and supports aim primarily to strengthen a family's capacity to build both informal and formal networks of resources to meet needs. (p. 118)

Keeping this description in mind, the remainder of this chapter presents information in an attempt to help develop a way of thinking about families of individuals with autism that will assist the professional in developing truly family-centered supports.

CHALLENGES FACED BY FAMILIES

We briefly consider the situation of a young man with autism and his family, whom we know. Christopher lives with his mom, dad, and younger sister, Cate. Christopher, nearly 10, is like many 10-year-olds, except that he presents a number of unique and specific challenges to this family. Consider for a moment several of the challenges Christopher presents to his family:

- Christopher usually sleeps in an erratic pattern: 2 hours of sleep alternating with 2 hours of wakefulness throughout the night.
- Christopher is easily upset by changes in family routines, even changes in the television schedule. He shows his distress by screaming and slapping his hand against his head.
- Christopher has been referred to numerous medical, psychological, and educational clinics, taxing not only the family's financial resources but also their time and energy.
- Christopher has unusual dietary habits. He only eats steamed vegetables with a side dish of butterscotch pudding and half a banana for dinner.
- Christopher regularly tears his clothes and does not seem content unless his shirt and pants are torn.
- Christopher is still not toilet trained, necessitating strained family routines and a constant supply of expensive adult-sized diapers.
- Christopher likes to run away when he is out of the house. When he runs, he likes to hide, and it usually requires an hour of frantic searching to find his latest hiding place.

Now consider that Christopher's family wants to provide a loving, nurturing home for him. Christopher's family, despite the challenges they face, are adamant in their resolve to provide for him at home, just as they do for his sister Cate. How can Christopher's family do what they know is best for him in light of the challenges they face?

A Lack of Support

The dilemma felt by families like Christopher's, who are caring for a child with a severe disability, can be lessened with adequate community support systems. The following sections of this chapter address some issues that have been assumed by professionals in the field to be sources of difficulty for families of individuals with autism, and a balanced look at some of the assumptions that are commonly held is presented. As a general statement, it is safe to say that a systems approach to viewing and supporting families and an orientation that focuses on maximizing the positive rather than on focusing on the negative has brought about a new appreciation of families.

Stress

Families who have a child with autism will experience emotional ups and downs during the period before the diagnosis is made (Wing, 2001). As autism is not yet detectable at birth and is typically not diagnosed before the age of 18 months, early identification of autism in the young child and the selection of appropriate interventions are ongoing challenges for parents and professionals.

Robins, Fein, Barton, and Green (2001) point out that that there is often a gap between the point at which the parents are first concerned about their child's development and the point at which a diagnosis of autism is made. This delay can cause families to experience additional stress and also means that early intervention services are not available as soon as they could be (Robins et al. 2001). Researchers have recognized the need to refine the instruments to facilitate the early identification of young children with autism.

Once a diagnosis has been made, the parents will experience emotions common to all parents of a child with a disability. This is an extremely stressful time because they are faced with determining the child's health problems, their sensory needs, and their educational and behavioral needs (Edelson, 2003). Families will research information on the various teaching strategies that are available to their child. As there are a variety on the market, deciding which best meets the child's needs can present a challenge.

The daily routines at home may be disrupted and can impact the other children in the family. Parents of a child with challenging behaviors may find it difficult to perform the everyday tasks that families take for granted, such as a trip to the grocery store (Fox, Vaughn, Wyatte, & Dunlap, 2002). In addition, the need for parents of children with disabilities to have some relief from the day-to-day responsibilities of caring for their child has been widely recognized.

Although parents are required to be invited to participate in the educational assessment and planning process for their child, this also can present its own challenges. An Individualized Family Support Plan (IFSP) or an IEP meeting is typically composed primarily of professionals. However well informed parents are, they may sometimes feel that their "voice" is not heard.

As their child grows older, parents will be involved in preparing for transition to services after high school. Decisions will need to be made regarding where their child will live and work and the ongoing supports that they may need. Each stage of the child's life will present new challenges for the family.

Financial Issues

The financial difficulties related to childrearing that face many families are very often more intense and long lasting for families who have a child with autism. Seligman and Darling (1997) differentiated between direct and indirect costs to families.

Direct costs to families are those expenses that are incurred for the costs of direct care, including training therapies and medically-related equipment and supplies that are not covered by private insurance or public assistance. Additional expenses come in many forms, including costs for medical and psychological assessments, trips to out-of-town clinics, and expenses for special diets and training programs. Many families who have children with autism who are not toilet trained report extraordinary expenses with diapers, clothing, and laundry expenses. Some children with autism have destructive tendencies, which result in the need to replace household items, and some families report the need for environmental modifications to their homes. Other families may pursue the latest therapy for their child, which may involve traveling to other states if it is not available within their own community. Such costs can total hundreds of thousands of dollars over an individual's lifetime.

For other families, direct costs might actually be minimal. A critical thing to keep in mind is that not only are the costs variable from one family to the next, but also even the effects of a given cost on the economic situation of a family vary from one family to another and at different points in the child's life.

An often unconsidered set of costs to families is *indirect costs*. Rather than out-of-pocket expenses, indirect costs are those hidden costs that are difficult to estimate. They may include the costs of the family moving to a particular community because of the availability of specific programs or services. Indirect costs may also include the costs to the family of opportunities foregone because of the needs of the family member with autism. These might include the economic losses to the family when one parent cannot

work outside of the home in order to provide care to the child. When the child is young, there is the need to provide before and after school care, and when they have graduated, the young adult may need continued supervision in the home environment. Professionals often overlook such costs when they consider the financial effects of the presence of a family member with autism.

Shopping for Services

In the past, the "shopping behavior" of parents of children with disabilities was viewed by professionals as an unhealthy behavior. Professionals felt that it was part of the "denial" stage of grieving and that parents were looking for further opinions from professionals to find a more acceptable diagnosis or treatment for their child (Anderson, 1971; Bicknell, 1983; Davidson & Schrag, 1968; Patton, Payne, & Beirne-Smith, 1986).

Today it is more acceptable and even expected that parents seek information and professional opinion from various sources. First, they may be seeking an accurate initial diagnosis, as some physicians may be hesitant to provide one. Second, they may be seeking second opinions, encouraged to do so by practitioners in the medical community and even by insurance companies (Ackerman, Lyons, Hammer, & Larsen, 1988; Sample, 1991). Third, the increase in the popular literature and media coverage of new therapies and interventions for children with autism may encourage families to shop around. As one parent described it,

> I sometimes feel like I am the teacher of the teacher, the doctor of the doctor, the expert in adapting family life to a disability, the source... of everything. If I didn't "shop," as you call it, my kid wouldn't get diddley. And that's the truth! (Sample, 1991)

Positive coping strategies that entail an active problem-solving approach and a sense of gaining "control" over an overwhelming situation have been identified as promoting family functioning (Turnbull & Turnbull, 2001). Parents are encouraged to be advocates for their children, to be informed about their choices, and to be active participants in the educational process.

THE FAMILY AS A SYSTEM

Family systems theory (Minuchin, 1974; Neugarten, 1976; Turnbull, Summers, & Brotherson, 1986; Turnbull & Turnbull, 2001) serves as a potential foundation for the understanding and examination of dynamics within the family

that has a child with autism. The basic premise of the family systems theory is that each family is unique, and that within the family constellation, each member contributes to the overall composition thus influencing all aspects of the family. Likewise, each family member is influenced by all other members of the family system and by the system as a whole.

Turnbull and Turnbull (2001) use family systems theory to conceptualize families with a member who has a disability. This conceptual framework consists of four major components: family resources, family interactions, family functions, and family life cycles.

Family Resources

All individual members of a family have personal characteristics that make them distinct from others in the family system. These descriptive characteristics, *family resources*, are the abilities, resources, and capacities of the family to meet the needs of each individual family member and also of the family as a whole (Turnbull & Turnbull, 2001). Characteristics pertaining to the family (e.g., size, socioeconomic status, ethnicity, geographic location), disability (e.g., type, level of ability), and personal condition (e.g., health status, individual personality characteristics, coping strategies) are considered family resources—those abilities, strengths, and skills the family possesses to meet both individual and family needs. Cultural style, ethnicity, and religion, as well as the members' beliefs and values, contribute to the family system and its resources. Obviously, this constellation of family resources is different from one family to another and needs to be viewed positively.

Family Interaction

This is the focal point of the family system and consists of those relationships that are related to the daily activities of the family. Each family is a system with four major subsystems: marital, parental, sibling, and extrafamilial (entire family or individual member interactions with family members, friends, professionals, and people within the community; Turnbull, Summers, & Brotherson, 1984). As noted by Turnbull et al. (1986), the family systems framework incorporates the premise that all living systems have interdependent components and that the "interaction of these parts creates properties not contained in separate entities" (p. 46). Therefore, it is difficult, if not impossible, to consider the actions, needs, or desires of one part of the family without first considering the family as an interconnected system. The individual needs of family members can only be understood by studying the relationships and interactions among family members. These family subsystems (i.e., parent–child, sibling–sibling) interact according to rules of

cohesion, adaptability, and communication. *Cohesion* describes the degree of closeness or distance among family members. *Adaptability* is the degree of family stability and reaction to change, and *communication* is the degree of honesty and frankness among family members.

Family Functions

Family functions are those needs that the family possesses that must be addressed. These functions, tasks, or output may be economic (e.g., generating financial resources), domestic and health care (e.g., locating appropriate health care providers), recreational (participating in community arts or sporting events), socialization (developing and nurturing friendships), self-identity (developing a thorough sense of self), affection (acknowledging others), and educational and vocational (securing training and employment that a person enjoys).

Family Life Cycle

Needs and perceptions change during the life cycle or developmental stages of each family (Carter & McGoldrick, 1999). Although there have been numerous descriptions of the stages in a family's life cycle, as early as 1986, Turnbull and Turnbull suggested four stages within the family life cycle: early childhood (when children are born and up to 5 years of age), childhood (when children are approximately 6 to 12 years old), adolescence (when children are approximately 13 to 21), and adulthood (when children are older than 21). For all families, the point at which they find themselves in the family life cycle has a great impact on many aspects of their functioning as a system. Professionals need to keep in mind that the family as a whole progresses through these stages at somewhat differing rates. Finally, it is important for professionals to also keep in mind the potential overlapping nature of these described stages.

Family Dynamics

To meet the needs of family members with compassion and understanding, professionals must consider the dynamics of individual families, their unique needs, characteristics, strengths, values, resources, and their particular stage within the family life cycle. Families who have a child with autism are like all families because their needs vary. Each family is unique. Within a family, numerous characteristics influence how the family reacts to autism, how family members cope, and how they face the challenge of incorporating the

child into the structure and function of the family. It should be remembered that families display both vulnerability and strength. Featherstone (1980) spoke of solitude, loneliness, and the fear of being a parent of a child with a disability. She reminded us, however, that parents and families endure and learn to live within the challenge of the disability, and even flourish because of it.

A Special Part of the Family System: Parents

Historically, it has been acknowledged that, in most families, primary child-care responsibilities were accomplished by mothers (Nye, 1976). Given this situation, in the consideration of parenting of family members with autism, most of the research attention has focused on the activities, needs, and feelings of mothers. In the 1990s there emerged an interest in the fathers of children with disabilities, including those with children with autism (Meyer, 1995; Turbiville, 1994). The nature of this research with fathers has been similar to much of the earlier research conducted with mothers of children with disabilities. It has been focused on differences, such as efforts to determine how fathers differ from mothers in regard to parenting issues (Elder, Valcante, Groce, Yarandi, & Carlton, 2002; Roach, Orsmond, & Barratt, 1999), or how the fathers of children with a particular disability differ from other fathers (May, 1997). As an example, among their findings, Milgram and Atzil (1988) stated that the mothers of children with autism expressed that life satisfaction is associated with relative contributions to overall parenting, whereas fathers of children with autism expressed that satisfaction is associated with their absolute parenting effort. According to Milgram and Atzil, these findings indicated that "mothers' life satisfaction was enhanced by fathers assuming a smaller, but fair share of child care" (p. 422). One would think that the statement applies to two-parent families in general, rather than being specific to families with children with autism or other disabilities.

Research that takes a deficit-oriented approach appears to have limited utility in consideration of how best to support families of individuals with autism. With both mothers and fathers, there is a need to refocus attention on strengths, capacities, and the contributions of both as individuals and as part of a whole family system. Similarly, much more needs to be known about how to best support single-parent families, regardless of the presence of a family member with a disability.

An important consideration in supporting two-parent families is the change that has been occurring in the last few decades in regard to the roles of mothers and fathers in general. Increasing numbers of mothers are working outside the home. At the same time, fathers are taking an increasingly

active role in parenting. There is a less clearly differentiated gender-related role separation in parenting than has existed previously. These changes are not specific to families of individuals with autism; rather they are occurring in all families. In 2004, because these societal changes are in flux, it is important for professionals who are attempting to support families to be aware that not only will there be potentially large differences among families in regard to the involvement of mothers and fathers, but also there can be a great deal of change over time.

One of the challenges facing all inexperienced parents, including those who have a child with autism, is to determine what is common, rather than *special* or highly unusual, about their family. It is especially difficult for inexperienced parents to gain perspective on the wide variety of novel encounters that they have. For this reason, it is helpful to hear stories of other families (Dillon, 1995) to put into perspective that feeling of "Are we the only ones who ever had something like this happen to them?" Although specific questions may be difficult to anticipate and ask, having access to common questions can often be helpful (Hart, 1993; Meyer, 1995; Powers, 1989).

A Special Part of the Family System: Siblings

Brothers and sisters of people with disabilities are unique and vital components of the family system (Powell & Gallagher, 1993). Sibling relationships, a critical component of a child's overall development, take on special significance when one of the siblings has a disability.

As Powell and Gallagher (1993) noted, the sibling relationship is perhaps the most long lasting and most influential relationship in one's life. It begins with the birth of a brother or sister and continues throughout life. The duration of the relationship is certainly substantial. Unlike parental relationships that may last 50 to 60 years, the sibling relationship may last 70 or 80 years. Unlike other relationships among people, the sibling relationship provides two people with physical and emotional contact at critical stages throughout their lives. Siblings provide a continuous relationship from which there is no annulment. This permanent relationship allows two people to exert considerable influence over each other through longitudinal interactions.

Research on sibling relationships provides evidence that there can be both positive and negative effects for the sibling of a child with a disability; that is, living closely and intensely with a sibling with a disability can be both rewarding and stressful (Helff & Glidden, 1998; Kaminsky & Dewey, 2001; Powell & Gallagher, 1993). On the positive side, many siblings report satisfaction in learning to live and cope with the demands of a child with a disability in the family, resulting in feelings of warmth and compassion

for all individuals with unique needs (Kaminsky & Dewey, 2001). It is helpful to envision the effects of a child with autism on a sibling as a continuum, with very positive outcomes at one end and some negative outcomes at the other (Powell & Gallagher, 1993). This continuum of outcomes for siblings is not static. A sibling may have a healthy, positive relationship at one time and yet, at another time, the same sibling may express negative behaviors and feelings toward the child with a disability (Powell & Gallagher, 1993). Such adjustment, of course, also affects the overall family system. Several factors contribute to determining where the nondisabled sibling functions on this continuum at various points in time. These factors include family characteristics, characteristics of the nondisabled sibling, and the characteristics of the child with the disability.

Powell and Gallagher (1993) described a number of special concerns and unique needs experienced by siblings. Although these concerns and needs are by no means limited to autism, their universal applicability provides a foundation from which to understand and address the needs of this special part of the family system. Siblings of children with disabilities are typically concerned about six broad themes:

1. *The child with the disability*, including the cause of the disability, the child's feelings, needed services, and what the future will hold
2. *Their parents*, including varying parental expectations, communications, the parents' feelings, and the parents' time
3. *Themselves*, including their feelings, their health, and their relationship with the sibling
4. *Their friends*, including informing their friends, handling teasing, their friends' acceptance of the disability, and dating
5. *The community*, including school services, community acceptance, and community living
6. *Adulthood*, including guardianship, financial responsibility, continuing their involvement, and genetics

In addition to these broadly described areas of concern, siblings, including those with a brother or sister with autism (Harris, 1994), have expressed a number of unique needs, including:

1. *The need for information.* Often siblings need and want information regarding the disability. Consider what 16-year-old Ellen Macfarlane (2001) had to say regarding her sister Anna, who has autism.

> "If I could suggest one thing about being able to understand children with autism or any people with disabilities, whether they are family or not, I would suggest knowledge. I find the reason we don't understand

certain things is we lack education. When people don't understand a disability, the person with the disability may be labeled as a 'retard' and not a person." (p. 190)

2. *The need for respect.* Like all people, siblings need to be respected as individuals, separate and apart from the disability. They need to be recognized for their own accomplishments.
3. *The need for skills.* Many siblings report a need to learn specific skills to assist them with their interactions with their brother or sister with autism. The more severe the autism, the more critical skill training for siblings appears to be.
4. *The need to share feelings and experiences.* Many brothers and sisters report a need to share their experiences and feelings with others.

A Special Part of the Family System: Extended Family Members

When professionals consider the family that has a member with autism, they are generally concerned with the nuclear family. Consideration is beginning to be given to the members of the extended family. The research regarding the concerns and needs of extended family members has included grandparents (Hastings, 1997). Grandparents are a critical part of the family system; however, there is also the need to consider other members of the extended family, such as aunts, uncles, and cousins. In addition, an appropriately scaled consideration of extended family must go beyond relationships by blood or marriage. With the increased mobility of families, the functions that may be served by relatives are often accomplished by friends. Any consideration of extended family must, thus, use the family's definition of members for inclusion.

Extended family members can provide support in a variety of ways. They might provide respite, temporary financial assistance, or an opportunity to listen and reflect family members' feelings. For professionals, it is important to recognize the real and potential support that might be available through this extended family network. At times, one of the best types of support a professional can provide to a family is to assist them in activating the support available through an extended family network.

In addition to the potential support for immediate family members from the extended family, supporting professionals should keep in mind another issue. Grandparents especially may have some of the same needs for support as other members of the family. Truly supporting the family means supporting all members of the family. Finally, it must be recognized that grandparents may also become a source of stress (Seligman, 1991) for the family who has a child with autism.

PROVIDING HELP: FAMILY SUPPORT SERVICES

It is clear that families with children with autism need flexible community support systems. Family supports include both formal and informal networks that can build the family's capacity to successfully meet their various functions (Dunst, 1995; Turnbull & Turnbull, 2001). Informal supports, such as friends, extended family members, church, and community service organizations, offer natural supports that should be promoted and enhanced. These informal supports can compliment the formal supports offered by community organizations.

Family support services provided by community organizations are dedicated to strengthening the family's ability to provide care for the child as much as possible within a family setting. Dunst (1995) suggests that family-centered support programs can be recognized because they:

- *Enhance a sense of community*—They promote the coming together of people around shared values and common needs in ways that create naturally beneficial interdependencies.
- *Mobilize resources and supports*—They build support systems that enhance the resources in ways that assist families with parenting responsibilities.
- *Share responsibility and collaboration*—They involve the sharing of ideas and skills by parents and professionals in ways that build and strengthen the collaborative arrangements.
- *Protect family integrity*—They respect the family's beliefs and values and likewise protect the family from intrusion upon its beliefs by outsiders.
- *Strengthen family functioning*—They promote the capabilities and competencies of families to mobilize resources and perform parenting responsibilities in ways that have empowering consequences.
- *Adopt proactive program practices*—They adapt consumer-driven service delivery models and practices that support and strengthen family functioning.

Key Support Services for Families With Children Who Have Autism

To adequately address the varying needs of families, support services must be designed and provided in a manner that allows for flexibility. Singer and Irvin (1991) noted that families use and appreciate services that allow them greater choice. In addition to providing choice and flexibility, the family support service must allow for full family participation in the design and monitoring of the program.

The following family support services can have beneficial effects in assisting families.

Individualized Services for Young Children

Strain, Wolery, and Izeman (1998) point out that services for young children need to be individualized to meet their needs and the needs of their family. They also suggest that families need guidance in deciding which intervention is appropriate for their young child. If, for example, the intervention suggested requires 30 to 40 hours of therapy a week outside of school, with an additional expense and time commitment from the family, this may be more than the parents feel is reasonable.

Although early intervention services are typically provided with no cost to the family, there may be additional costs for certain therapies. Mandlawitz (2002) reviews a number of court cases involving the provision of services to young children with autism. She points out that in many of these cases parents want reimbursement for programs that they have initiated at home, including applied behavior analysis (ABA) and discrete trial training (DTT). Strain and his colleagues (1998) suggest that interventions be demonstrated not only to be effective but also to see whether they match a family's needs, values, and resources.

Researchers continue to maintain the position that parents play a central role in the education of the young child with autism, particularly in the areas of the development of communication. Siller and Sigman (2002), for example, investigated the parents' role in play interactions with their children and its effect on the child's language development, and Bruns and Gallagher (2003) developed a process to facilitate communicative behaviors of young children implemented both at home and at school.

The preschool services that are available for the young child with autism may also vary depending not only on where the family lives but also on the program philosophy. For example, Handleman and Harris (2001), in their description of preschool programs across the country, show that on the issue of inclusion there are varying degrees of integration of children with disabilities with their same-age peers. For parents of a young child with autism, their choices may be restricted to what is available in their own community.

Financial Assistance. Many states offer some form of financial assistance to families who have children with disabilities. These financial assistance programs are often in the form of cash assistance to the family, payment for needed support services, or a combination of the two. Receiving financial assistance in any form enables a family to have control and flexibility over the services they need to maintain quality of life at home as a family unit (Agosta & Melda, 1995).

Parent Education. One main support that has been provided to families is parent education. Parent education programs are aimed at providing both

information and education on the skills they need at home to help their child. Today, there is greater recognition that parent education programs need to be designed to fit into the natural routines of families' lifestyles (Koegel, 2000; Moes & Frea, 2000). Many of the efforts to provide parents with training have focused on teaching parents and even siblings, in some instances, the skills of applied behavior analysis (Hastings & Johnson, 2001; Lovaas, 2003). Parents using behavior teaching strategies have been able to enhance child performance in such areas as communication skills, self-help skills, social skills, and academics, as well as teaching the child acceptable forms of behavior. Behavioral parent training can provide a structure to help many parents become efficient and effective teachers of their children; however, it is not without its critics.

Turnbull and her colleagues (1986) cautioned that overemphasis of behavioral parent training may relegate the parent to a surrogate teacher position. They warn that these highly structured approaches may distort the parent–child relationship and cause more stress within families. They urge methods that enhance the typical, informal parent–child teaching interactions that include affection, playing, and joking. Because parents have many essential roles to fulfill, behavioral parent training may simply require a commitment of time, resources, and, in some instances, a financial commitment, which some parents are not able to make.

In response to this criticism, some researchers have implemented parent training programs that focus on the use of more natural instruction within the normal family routine. Singer and Irvin (1991) report several successful approaches to help parents improve teaching skills within the natural setting and everyday situations.

Several new intervention approaches have emerged in recent years. These include the use of functional communication training to manage challenging behaviors (Moes & Frea, 2002), facilitated communication to assist in communication (Biklen, 1993; Mostert, 2001), social stories to manage behavior (Kuttler, Myles, & Carlson, 1998; Scattone, Wilczynski, Edwards, & Rabian, 2002), auditory integration therapy to manage behavior (Berard, 1993; Bettison, 1996), and sensory integration (Case-Smith & Bryan, 1999). Through the Internet, parents can readily access information on a variety of intervention strategies. Parents need information about techniques that are available but they also need information about how to evaluate the effectiveness of these new techniques. For example, Mostert (2001) reviews the literature on facilitated communication and shows that more scientific work needs to be done on this technique. He suggests that the nature of autism and the challenges that it presents to teachers and parents lends itself to what he describes as the search for a "'silver bullet' cure."

The worldwide increase in the numbers of children identified with autism (Croen, Grether, Hoogstrate, & Selvin, 2002) can give more urgency to the

need to find proven strategies. Goldstein (2000) highlights the problems facing both parents and professionals:

> Should we condone families expending their precious psychological and financial resources or condone scientists expending their precious time and energy on treatments that are too good to be true? Can we allow anecdotal reports, case studies, and uncontrolled experiments to continue to guide the field and the families of children with autism? (p. 424)

Professionals therefore have an obligation to give parents not only information about various strategies but also information on how to evaluate them. A comprehensive parent education program should include information on autism; information on community supports available to the family; skills development to enhance parent–child, child–child, parent–parent, and parent–professional interaction; information on rights, entitlements, and public laws; strategies to help parents manage time, resources, and competing needs; and information on transition and future needs and service options for persons with autism. Parent education must not be conceptualized as one-way delivery with the professional imparting information and skills to parents. Parent education programs that make a difference in supporting families realize that professionals also need to learn from families.

Respite Care. When a child has autism, parents very often have a difficult time finding babysitters to allow them breaks from parenting responsibilities. Most would agree that such breaks are essential for all parents, and even more so when a child has a disabling condition. Respite care is more likely to be helpful to families if it is delivered as part of a comprehensive support program. Respite care should be designed to allow parents the greatest amount of control over how the respite is provided and flexibility as to when the respite is available and used.

Advocacy. Many families of children with autism find that they must confront and challenge the service delivery system in order to secure services for their children. Parents are the best long-term advocates for their children. The IDEA recognizes this by affording parents specific rights under this law to actively participate in the identification of the needs of their child and the design of their IEP. States have developed Parent Information and Training Centers specifically designed to provide information and training to parents on their rights under the special education law. Today, these centers typically provide a wealth of resources to parents.

Mutual Support Networks. Many families report that they find support from other parents to be an essential component of their support networks.

A number of support networks have arisen among the perceived support needs of families who have a family member with a general or specific disability. Parents of children with similar disabilities can not only share experiences but also provide mutual emotional support and information about strategies and services. Professionals can support families by being aware of mutual support networks in order to inform families of their existence and availability. Today families can access support networks on the Internet, even if there is no immediate group in their area. There are several national organizations, which can provide general information to parents of children with disabilities and specifically to parents of children with autism. A list is provided at the end of this chapter.

Supports for the Future

Earlier in this chapter, reference is made to constant concern in regard to the future of the family member with autism. Professionals can support families in planning and preparation for the future through the activities discussed here.

Transition Planning

As a child with autism enters the adolescent period, the topic of transition services will be increasingly important and this can present families with new challenges. Transition occurs at various stages in school with one formalized period of transition in adolescence. The IDEA requires that students with an IEP begin this process at age 14 (Storms, O'Leary, & Williams, 2000). The transition period presents families with new information and requires the family and their child to think about future options and to plan for them within the IEP (Morningstar, Turnbull, & Turnbull, 1995). Adolescence is typically a time of transition for all families as adolescent children find their own identities and grow independent of their parents. Parents of a child with autism face not only the same emotional challenges as do all families but also the prospect of having their children dependent on them for a much longer period of time. They are required to project into the future about where their son or daughter will be living and working and become informed about the range of options that will be available. They discover not only that there is a range of possible adult service providers but also that there is no automatic entitlement to services. Their son or daughter will have to meet eligibility requirements for each adult service. In many instances they will discover that there are waiting lists for many services. No wonder this period is particularly stressful for families—The support they need from professionals at this time is information about the range of options for their son or daughter and how to access them.

A key component to the transition process is self-determination. This is reflected in the IDEA, in that students are always able to participate in their IEP. At age 14 students are required to be invited independent of their parents when transition planning. The law requires that a student's preferences and interests be documented in the IEP as part of the transition process. The culmination of this process is that, when the child reaches the age of majority, rights transfer from the parents. At this point some parents may consider applying for guardianship if they feel that their son or daughter is unable to make informed decisions on their own.

So the focus shifts from exclusive parent participation to include the participation of the student in his or her own right. All parents recognize that this is an accepted part of adolescence—a child coming into his or her own and making his or her own decisions. For parents of a child with autism, this period can present conflicting emotions such as the desire to see the child grow up and become an adult countered by the recognition that, to achieve this, the child may need ongoing supports from the family.

Estate and Financial Planning

As the child with autism matures, family concerns tend to focus on future arrangements for the individuals when parents and other family members are not available. Given the rapid changes in social services policies, benefits, and community services, future estate and financial planning is a strategy step to help ensure this family member's future.

Estate and financial planning are typically done via wills and trusts, but these are not usually sufficient to ensure a secure future for the person with the disability. Self-sufficiency trusts are an option that allows families to set aside resources that do not interfere with the individual's benefits and are used to provide services and materials to enhance the family member's quality of life, which may not be able to be provided from other resources.

A CALL TO ACTION—BEING AN EFFECTIVE FAMILY HELPER

The professional needs to go beyond a mere recognition of the needs of families and understanding of the systems that influence families. The professional must exhibit a number of key characteristics that enhance family functioning. Although not an exhaustive list, we believe the following characteristics are germane to the professional who wishes to help families who have children with autism.

Respect Families

Professionals must first and foremost respect the family as a unique system, and respect and recognize the individuals who comprise that system. The professional must demonstrate a positive respect via words, actions, and direct assistance provided.

Trust Families and Be Trustworthy

Trust is the basis of effective communication. Professionals must be individuals who can be trusted by family members. Likewise, the professional must be able to be trusting of others. The professional must exhibit confidence in family members.

Presume Health

Effective helpers will not presume that the family is somehow "sick," but rather accept a posture that the family has unique needs because of the family member with autism. They must recognize that those needs vary from family to family. Effective professionals reject the pathogenic notion of autism.

Praise and Encourage

All too often, family members never hear words of praise or encouragement. They hear reports of the child's problems. They hear blame. They hear words of despair. Effective professionals have an understanding and appreciation for the many demands placed on family members and they recognize accomplishments within that context. They seize every opportunity to recognize the accomplishments of the family members.

Be Empathetic

A key characteristic of effective professionals is an ability to understand families. The professional who demonstrates empathy and an ability to understand the needs and feelings of others will be effective with the families he or she wishes to help. An understanding of the family, its interactions, needs, joys, feelings, and attitudes will help the professional provide the necessary support within a context that can be utilized and understood.

Behave Ethically

The title "professional" implies strict adherence to a set of ethical principles of the profession. Family members have a right to expect professionals to behave in accordance with the highest standards expected in the profession. Chief among these are:

- *Maintaining confidentiality.* The family must know that the professional will never breach the family's confidence. Information about the family must be shared only with permission and then only with other professionals who have a clear need to know.
- *Staying current.* Professionals must keep their skills and knowledge up to date. Professionals who provide erroneous information or lack current skills do a severe disservice to the family. Professionals must ensure that their knowledge and skills are continually being developed.
- *Promoting the interest of the family.* Professionals must always put the needs and interests of the family before any personal or self-interests. Similarly, the professional cannot permit bureaucratic or agency interests to diminish efforts to support families.

Be Gentle

Families who face harsh realities do not need harsh professionals. Families need sensitive professionals who practice gentle intervention. Gentle intervention does not imply a less-than-aggressive approach to family support. It does imply intervention that is sensitive to family needs and the demands faced by the family. Gentle intervention means using and strengthening natural supports, using sensitive language, listening, and, when possible, working behind the scenes to help families. Gentle intervention also implies arranging meetings that are sensitive to the needs of the family.

Limit Demands

Professionals who understand the pressures experienced by families will work to limit extra demands. Effective, empathetic professionals seek ways to support families without adding to their burdens.

Be Oriented Toward the Future

Families need professionals who are focused on the future, not those who continually look at the past. The effective helper will use the present to

prepare the family and individual with autism for the future while helping to shape that future.

Be Optimistic

Families often find themselves surrounded by professionals and friends who convey a pessimistic attitude. They receive sympathy and hear words like "Too bad," "I'm sorry," and "How do you ever do it?" Although well meaning, these statements do little to support the family and can engender despair. Such pessimism is commonly compounded by negative evaluations that focus on the family member's deficiencies. Effective professionals are optimistic about the future. They convey hopeful, optimistic messages that are matched with energy, skill, zeal, and commitment to work for positive futures. Effective professionals focus on the positive attributes of the individual with autism and build on the person's strengths.

FUTURE DIRECTIONS IN SUPPORTING FAMILIES

We have come a long way in the support of families who have children with autism. No longer are parents held responsible for the cause of autism, and there is common acceptance of the family's right to be supported. However, there is still a long way to go before all families with children with autism are afforded positive futures. In the immediate future, specific attention should be given to the following areas:

1. *Support to extended family members.* Grandparents, aunts, uncles, cousins, nieces, and nephews all are affected in one way or another by the presence of autism. Extended family members can be a major source of longitudinal and natural support to immediate family. To facilitate this, we need to find better ways to understand and address the needs of extended family members and provide them with necessary support.
2. *Support to single parents.* A growing phenomenon in our society is the single-parent household. Although there is greater recognition of the special needs of the single-parent household, much of the research and demonstration work has concentrated on the traditional, two-parent family. Much more attention needs to be given to support strategies to help single parents of children with autism. Likewise, special attention must be given to the divorced parent who no longer lives with the child with autism. The parenting responsibilities of the divorced father or mother take on new dimensions when the parent may only see the child for short intervals. We

need to recognize the importance of these parents and seek strategies to meet their needs.

3. *Natural supports.* The best support seems to be that which comes from natural sources, like family and friends, as well as generic community services. If we are to capitalize on these, we need to formulate better ways to help all families access this support. We need to investigate barriers to developing natural support and discover the types of natural support that are best suited to different families and different times. We need to help community supports include all who may need support, regardless of disability.

4. *Determination of needs.* Now that we recognize that families are indeed different and thus have different needs, we need to develop systematic ways to find out what those needs are for each family. Such strategies will be helpful in the development of new support services and public policy aimed at strengthening families. We need to be asking families what they perceive their needs to be and what kind of preferences they have in the ways they receive support (Seligman & Darling, 1997; Summers et al., 1990).

5. *Rural families.* Much of the present work with families has been done with those residing in either large metropolitan settings or suburban communities. The family with a child with autism living on an isolated ranch or in a small rural community is often most neglected. How can we better develop support services and policies to allow families to choose a rural lifestyle if they have a child with autism and need support?

6. *Transition to adulthood.* Challenges faced by families of children with autism continue but change as their children approach and enter adulthood. Estimates are that as few as 25% of adults with severe disabilities of various kinds and 8% of adults with profound disabilities are employed (La Plante, Kennedy, Kaye, & Wegner, 1996). These dismal employment statistics are further evidence of the need for helping families when considered in light of the increasing numbers of inclusive school-based programs that are being made available to families (Certo et al., 2003). There are numerous recent efforts to ameliorate this situation. As an example, Certo et al. describe a promising new approach to planning for adult needs and services, called the "Transition Services Integration Model." In this approach to planning for adulthood public schools, rehabilitation services and developmental disability systems work in partnership to integrate resources and expertise for individuals with significant needs. Additional information about challenges and opportunities specific to transition to adulthood for individuals with autism can be found in chapter 13 of this volume, "Community Integration, Supported Employment, and Adult Living."

7. *Quality indicators.* As family support services are further developed, quality indicators need to be established that will guide the service delivery. What does "quality" imply? How do we recognize a quality program? Do we all agree on indicators for quality family services? Although many purport

to provide family support services to those with autism, families and professionals should monitor and control the quality of those services. We need mechanisms that will help families and those who provide funding to recognize quality family services. Such an assessment and monitoring technique has been suggested by Murphy, Lee, Turnbull, and Turbiville (1995).

HELPING FAMILIES BUILD A POSITIVE FUTURE

Autism historically was plagued with a negative attitude toward parents and a general disregard for family members. The old assumption that parents were to blame for autism has yielded to a more enlightened and helpful attitude that parents and family members need to be aggressively supported. Family support needs to be provided in a manner sensitive to the family system, taking into consideration the family's beliefs, values, development, needs, membership, and major functions. Proactive family support is focused toward the future and is implemented by caring and competent professionals who appreciate the value of the unique relationship we call the parent–professional partnership. We now take a quick look into the future to see what it could hold for Nick, Tim, and Sarah, and their respective families.

Given creative supports from flexible systems and effective professionals, for Nick and his family the future looks bright. Nick now has a real job that pays him just about enough to make ends meet. That's good because he doesn't need to use all of his earnings to pay bills. Nick also gets some financial support that permits him both the freedom to pay for necessities and also for things like recreation and a vacation. He's lost weight and looks fit. Two evenings a week, Nick takes classes at the community college. He is particularly fond of the classes that he has taken there—after all, that is where he met his fiancée. Nick's parents are very pleased that the programs supporting him did not give up on him.

Tim and his family are doing quite well also. Tim is going to the same neighborhood school that the other neighborhood children his age are attending. All the members of Tim's family think that the extended day and extended school year services have been the strongest factor in Tim's having mastered so many of the skills than even they were reluctant to guess that he would have mastered just a few years ago. Although school has been great, the real key for Tim and his family has been the live-in assistance that has been provided for them through a coordinated effort of several state and local agencies and their church. Not only has the live-in help relieved a great deal of anxiety that Tim's parents had about being able to meet the whole family's needs, but the tie-in with the school program has meant wonders for Tim's learning. The school district will actually say this has been a good program for all involved.

For Sarah and her family, the good things that started for them when she was very young continue to get better. Sarah and her family are fully included in all the community's school and recreation opportunities. Everyone knows her and accepts her. One of the especially nice things that has happened is that Sarah's outgoing family has been instrumental in the development of several mutual support groups in town. Sarah's parents helped start an information and referral system for professionals and families in the region. Sarah's brothers and sisters regularly get together with other children their own age who happen to have siblings who have a variety of disabilities to share information and support each other. Even Sarah's grandparents have gotten into the act and meet at the community center with other grandparents who have grandchildren with disabilities. Sarah's extended family has networked at many levels. Things are going splendidly for Sarah and her family.

We have hinted at some of the dreamed-of possibilities for three families. But, what about Christopher and his family? What will their future hold? We won't pretend to know, but we can hope. The challenge for professionals will be to support ALL families in flexible, creative ways. It is safe to say that in the future, families will be supported in ways we cannot begin to imagine, ways which will look more natural—ways that help these families be more a part of their communities rather than apart from their communities. Let this be a CALL TO ACTION to all who come in contact with Christopher and his family. Let them dream! Dream with them! Help them make those dreams reality!

INTERNET RESOURCES FOR FAMILIES

It is a challenge to provide comprehensive lists of resources because they can and do change. Consequently, this list is limited to just a few resources that have been quite stable over time, in addition to being extremely helpful for families. These select resources can also serve as contacts for further resources.

American Speech–Language–Hearing Association (ASHA)
www.asha.org
This association provides information on a variety of communication disorders and intervention strategies.
Autism Society of America
www.autism-society.org
The Autism Society of America was started by a group of parents working on a volunteer basis out of their homes. The Society has now developed

into a national support center, providing parents with information and referral on autism.

Beach Center
www.beachcenter.org
The Beach Center at the University of Kansas provides resources for families who have a child with a disability and conducts research into family issues.

Disability Resources
www.disabilityresources.org
Disability Resources has information on a wide variety of resources and support services.

Families for Early Autism Treatment (FEAT)
www.feat.org
FEAT provides information, parent support, and a newsletter to parents of children with autism.

Family Village
www.familyvillage.wisc.edu
The Family Village provides resources for families on disability-related topics including resources on specific diagnoses, educational issues, and health issues.

Fathers Network
www.fathersnetwork.org
The Fathers Network provides information and support to fathers of children with disabilities.

March of Dimes
www.modimes.org
The March of Dimes is a national nonprofit organization dedicated to sponsoring research into birth defects and to providing information to the community. The site has information on a range of disability issues.

National Information Center for Children and Youth with Handicaps
www.nichcy.org
NICHCY is the national information center that provides information on children and youth with disabilities (birth to age 22) and disability-related issues. Through NICHCY, families can find information on services and organizations in their state.

PACER center
www. pacer.org
The PACER center is a parent information and training center that provides resources to families with children with a wide variety of disabilities. Through this Web site families can access links to the parent information and training centers in each state.

Sibling Support Project
www.thearc.org/siblingsupport

The Sibling Support Project is a national resource program providing information, support, and education for sisters and brothers of people with special health and developmental needs.

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Part II

THE EARLY YEARS

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Chapter 5

Early Identification of Autism Spectrum Disorders

Elaine M. Gabovitch
Nancy D. Wiseman
First Signs, Inc., Merrimac, Massachusetts

WHY EARLY IDENTIFICATION IS SO IMPORTANT

Developmental issues in children are being reported in epidemic numbers and those numbers are growing. Autism is now the third most common childhood disorder, behind mental retardation and language impairment.

With proper intervention, a child can overcome a wide range of developmental problems. Intensive, well-designed, and timely intervention can improve the prospects—and the quality of life—for many children who are considered at risk for cognitive, social, or emotional impairment. In some cases, effective intervention can improve conditions once thought to be virtually untreatable, such as autism. Well-implemented programs can brighten a child's future and the impact a developmental disorder has on the family. They can lead a child to greater independence, enable that child to be included in the community, and offer a more productive and fulfilling life.

Unfortunately, many pediatric physicians fail to identify a developmental disorder, such as autism, at an age when the child should be receiving early intervention services. Birth to 3 is a critical time in a child's development, so a delayed diagnosis may compromise chances for success.

Physicians are the only professionals who have routine contact with all children prior to school entrance. They are required by Medicaid and urged by the American Academy of Pediatrics (AAP) to detect developmental and behavioral problems and refer children promptly to early intervention.

Although most physicians recognize the value of early intervention, they have significant difficulty identifying children with developmental delays and disorders. An important reason for this difficulty is the increasing time pressure placed on health care providers to improve their productivity, coupled with the fact that they may not know what critical signs to look for during each stage of development.

Often, physicians will not use developmental assessments because they require more time for observation than the typical provider is allowed; others use them, but often choose measures that are not sensitive enough to detect developmental delays and disorders. Still, some physicians believe a child's severe developmental disability will not be affected by early intervention, whereas others would rather not alarm the parents unnecessarily in case the child is able to overcome the disability. This may explain why detection rates of young children with developmental delays and disorders, including autism, are so low: Study after study show that 70% to 80% of children in need of services are not identified by their primary care provider. (Dobos, Dworkin, & Bernstein, 1994; Filipek et al., 1999). The average age at which a child is diagnosed with autism is 6 (Howlin & Moore, 1997). Consequently, children often miss important opportunities for assistance during the most critical time in their development.

CHARTING TYPICAL AND ATYPICAL DEVELOPMENT

During the first 3 years, children make many regular visits to the physician. Well visits provide regular ongoing opportunities to record history, observe the child, and monitor and chart a child's social, emotional, and cognitive development, and to screen for developmental disabilities. Although it is a challenge for both the parent and the physician to cover the wide range of issues related to a child's health within a limited time, screening can be simple and should only take a few minutes. Standardized screening is effective, because it observes major developmental milestones. It is important because of the potential each child holds—potential for success, for challenges, but above all, for change and development. To recognize a child's risk for developmental disabilities, then, is to also recognize and maximize a child's potential.

Parents are in the best position to observe and report what their child is doing. Sometimes they are satisfied; other times they are worried. However, the words "don't worry" have too often discouraged parents and have prevented many children with developmental disorders from getting what they need most—early screening and identification, and appropriate intervention. Despite the fact that there is a direct correlation between early identification and improved development, parents with concerns about their

children are often told not to worry. "Don't worry... boys develop more slowly. Don't worry... she'll grow out of it. Don't worry... Einstein was a late talker too. Don't worry... just give it a few months."

Imagine the following scenario: A young child has a persistent cough. The parent, concerned, schedules an appointment with a physician. The physician evaluates the child: Sometimes a cough is just a cough; other times a cough can be a signal of something more serious. Just as parents and physicians are careful to respond to a young child's physical health, they are wise to monitor a child's development of social, emotional, and communication skills. When parents report a persistent cough, they aren't told not to worry. They don't hope their child will outgrow it. They aren't concerned about labeling, over-reacting, or what their family might think. They know something is wrong. Parents simply act, based on their observations of their child. In turn, the physician examines the child and conducts the necessary tests to find out what, if anything, is wrong. If necessary, the physician will refer the child to a specialist. When developmental concerns are raised, the same course of action should be applied (First Signs, Inc., 2003).[1]

Monitoring Healthy Development Through Routine Surveillance

It is important to monitor a child's healthy development and to address concerns through the practice of routine developmental surveillance. The developmental surveillance process is one that calls on pediatric physicians to elicit, listen to, and address parental concerns; obtain full developmental histories; observe children carefully; and share their opinions and concerns with other relevant professionals (Dworkin, 1993). Observation by itself is not enough, because the warning signs of developmental concerns can be subtle and easy to miss without the use of a validated screening tool, especially to the untrained eye. By making developmental surveillance and routine developmental screening regular parts of office visits, the index of suspicion becomes heightened for physicians, helping them to sharpen their observations and to elicit better information about concerns from parents (AAP, 2001).

The most important way to monitor the healthy growth and development of a child is through an active partnership between parents and physicians. To this partnership, parents bring powerful observations and experiences, fortified by a sense of love and responsibility. A physician must ensure that the full range of a child's development—physical, cognitive, and social–emotional—is monitored at each well visit. Through observation,

[1] Much of the content in this chapter has been derived from the First Signs Web site at www.firstsigns.org.

measurement, screening, and listening and sharing with parents, a physician can evaluate a child's healthy development.

There is a wide range of what clinicians consider healthy or *typical* growth and development: One child walks at 9 months; another walks at 12 months. Milestones help establish the outer limit for the range of healthy development. But within the range of typical development, there is tremendous variation and great opportunity for individual difference. Although each child develops differently, some differences may indicate only a slight delay and others may be cause for greater concern.

The developmental checklist in Table 5.1 provides important guidelines for tracking healthy development from 4 months to 3 years of age (Greenspan, Prizant, Wetherby, First Signs, 2001).[2] This checklist is *not validated* and *should not be used in place of a screening*, but should be used as discussion points between parents and physicians at each well visit. If a child does not have the skills listed—or if there is a loss of any skill at any age—a formal screening should be initiated by the primary pediatric practitioners immediately (Filipek et al., 1999, 2000).

The Absolute Indicators

In clinical terms, there are a few *absolute indicators*, often referred to as *red flags*, that indicate that a child should be evaluated. Table 5.2 lists the red flags that indicate the need for immediate referral for a full diagnostic evaluation to ensure that a child is on the right developmental path (Greenspan, 1999; Filipek et al., 2000).[3]

Other Warning Signs

In addition to these well-documented absolute indicators, there are other warning signs that are frequently mentioned anecdotally by both parents

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[2] *Is Your Baby Meeting These Important Milestones? Key Social, Emotional and Communication Milestones for Your Baby's Healthy Development* (Greenspan, Prizant, Wetherby, First Signs, Inc., 2001) was a collaborative effort among First Signs, Stanley Greenspan, M. D., Barry Prizant, Ph.D., and Amy Wetherby, Ph.D. The milestones were compiled from the following sources: Greenspan, S. I. (1999). *Building Healthy Minds*, Perseus Books; Prizant, B. M., Wetherby, A. M., & Roberts, J. E. (2000). Communication Disorders in Infants and Toddlers. In C. Zeanah (Ed.), *Handbook of Infant Mental Health*, Second Edition, New York: Guilford Press; and Wetherby, A. M. (1999). *Babies Learn to Talk at an Amazing Rate*, FIRST WORDS Project, Florida State University.

[3] *Red Flags* were compiled from the following sources: Greenspan, S. I. (1999). *Building Healthy Minds*, Perseus Books; Filipek et al. (2000). Practice parameter: Screening and diagnosis of autism. *Neurology, 55*, 468–479.

TABLE 5.1
Is Your Baby Meeting These Important Milestones? Key Social, Emotional, and Communication Milestones for Your Baby's Healthy Development[a]

Does Your Baby...

At 4 Months:
- ☐ Follow and react to bright colors, movement, and objects?
- ☐ Turn toward sounds?
- ☐ Show interest in watching people's faces?
- ☐ Smile back when you smile?

At 6 Months:
- ☐ Relate to you with real joy?
- ☐ Smile often while playing with you?
- ☐ Coo or babble when happy?
- ☐ Cry when unhappy?

At 9 Months:
- ☐ Smile and laugh while looking at you?
- ☐ Exchange back-and-forth smiles, loving faces, and other expressions with you?
- ☐ Exchange back-and-forth sounds with you?
- ☐ Exchange back-and-forth gestures with you, such as giving, taking, and reaching?

At 12 Months:
- ☐ Use a few gestures, one after another, to get needs met, like giving, showing, reaching, waving, and pointing?
- ☐ Play peek-a-boo, patty cake, or other social games?
- ☐ Make sounds, like "ma," "ba," "na," "da," and "ga?"
- ☐ Turn to the person speaking when his/her name is called?

At 15 Months:
- ☐ Exchange with you many back-and-forth smiles, sounds, and gestures in a row?
- ☐ Use pointing or other "showing" gestures to draw attention to something of interest?
- ☐ Use different sounds to get needs met and draw attention to something of interest?
- ☐ Use and understand at least three words, such as "mama," "dada," "bottle," or "bye-bye"?

At 18 Months:
- ☐ Use lots of gestures with words to get needs met, like pointing or taking you by the hand and saying, "want juice"?
- ☐ Use at least four different consonants in babbling or words, such as m, n, p, b, t, and d?
- ☐ Use and understand at least 10 words?
- ☐ Show that he or she knows the names of familiar people or body parts by pointing to or looking at them when they are named?
- ☐ Do simple pretend play, like feeding a doll or stuffed animal, and attracting your attention by looking up at you?

At 24 Months:
- ☐ Do pretend play with you with more than one action, like feeding the doll and then putting the doll to sleep?
- ☐ Use and understand at least 50 words?
- ☐ Use at least two words together (without imitating or repeating) and in a way that makes sense, like "want juice"?
- ☐ Enjoy being next to children of the same age and show interest in playing with them, perhaps giving a toy to another child?
- ☐ Look for familiar objects out of sight when asked?

(Continued)

TABLE 5.2
(Continued)

At 36 Months:

- ☐ Enjoy pretending to play different characters with you or talking for dolls or action figures?
- ☐ Enjoy playing with children of the same age, perhaps showing and telling another child about a favorite toy?
- ☐ Use thoughts and actions together in speech and in play in a way that makes sense, like "sleepy, go take nap" and "baby hungry, feed bottle"?
- ☐ Answer "what," "where," and "who" questions easily?
- ☐ Talk about interests and feelings about the past and the future?

[a]This table was a collaborative effort among First Signs, Inc. and Greenspan, Prizant, and Wetherby (2000). Copyright 2001 First Signs, Inc.

and professionals. Table 5.3 indicates concerns that should commence the screening process whenever they arise.

Whenever concerns are raised about a child's development, whether by parent, caregiver, or physician, all parties should take immediate action. A developmental screening should be given right away.

Practitioners need to be vigilant of other causes, especially if there is a possibility of a differential diagnosis from other developmental problems, such as hyperkinetic and attentional disorders, language disorders, profound developmental delay, obsessive–compulsive disorder, motor disorders, as well as specific and general learning problems. Differential diagnosis can be especially difficult in young children with severe and profound developmental disability and in children with superior intelligence (Baird et al., 2001).

TABLE 5.2
Social, Emotional, and Communication Red Flags

If a baby shows any of the following signs, an evaluation should be conducted *immediately*:

- ☐ No big smiles or other warm, joyful expressions by 6 months or thereafter
- ☐ No back-and-forth sharing of sounds, smiles, or other facial expressions by 9 months or thereafter
- ☐ No babbling by 12 months
- ☐ No back-and-forth gestures, such as pointing, showing, reaching, or waving by 12 months
- ☐ No words by 16 months
- ☐ No two-word meaningful phrases (without imitating or repeating) by 24 months
- ☐ Any loss of speech or babbling or social skills at any age

Note: From *Building Healthy Minds*, by S. I. Greenspan, 1999, Cambridge, MA: Perseus Books. Copyright 1999 by Perseus Books, and from "Practice parameter: Screening and diagnosis of autism," by P. A. Filipek et al., 2000, *Neurology, 55*, pp. 468–479. Copyright 2000 by *Neurology*.

TABLE 5.3
Other Common Presenting Features That May Indicate the Need for Screening

Unusual Stereotypic Behaviors
- Has little or no eye contact
- Does not respond to name
- Has a language delay
- Does not share interest in an object or activity jointly with a preferred adult
- Displays rigidity and gets stuck on certain activities
- Expresses insistence on sameness and resistance to change
- Demonstrates inappropriate play or behavior
- Tantrums easily
- Has unusual motor behaviors or motor planning
- Odd hand and finger mannerisms
- Rocks or bangs head
- Lines up toys or objects in obsessive manner
- Lacks ability to play with toys
- Prefers to be alone
- Likes to spin self or objects
- Arches back
- Uses repetitive words or phrases (echolalia)
- Displays self-injurious behaviors

Sensory Aversions
- Over- or under-reactive sensory input (i.e., touch, sound, taste, sight, hearing)
- Overarousal and regulatory issues
- Difficulty processing sensory information

Physiological Concerns
- Abnormally accelerated rate of brain growth within first year of life
- Regression or loss of skills
- Low muscle tone
- Frequent ear infections
- Difficulty sleeping or unusual sleep patterns
- Frequent gastrointestinal issues (e.g., reflux, stomach pains, diarrhea, and constipation)
- Very picky or unusual eating habits
- Rigid preference for certain foods containing dairy or gluten
- Seizure activity
- Other disorder present, such as tuberous schlerosis, fragile X, or Landau Kleffner syndrome, that may be co-morbid
- Dysmorphic features

Other Concerns
- Younger sibling of a child with autism spectrum disorder
- Familial presence of other warning signs

THE SCREENING PROCESS

Key policy statements have been issued by the American Academy of Neurology [AAN], (Filipek et al., 2000), the AAP (2002), and the National

Academy of Sciences (2001) defining guidelines for screening and diagnosis of autism spectrum disorders. The following procedure supports standard practices among physicians to simplify the screening process and to ensure that all children receive routine and appropriate screenings and timely interventions (Filipek et al., 2000; First Signs, Inc., 2001a, 2001c, 2003).[4]

Screening Guidelines

1. *Make clinical observations and chart developmental milestones.* Physicians should take a brief moment at the start of each well visit to observe how the child behaves, interacts, and communicates with a parent or caregiver in either the reception area or the examining room. Use the developmental milestone checklist (Table 5.1) to refer to the social, emotional, and communication milestones for a child's age and discuss the child's development with the child's parents or caregivers. Because it is often difficult to pick up the subtleties of atypical development in a busy practice, measurement through a developmental screening tool is recommended as the most efficient and effective way to monitor a child's development.

2. *Conduct routine developmental screening.* A physician, nurse practitioner, or trained physician assistant should perform routine developmental screenings at each well visit on all children from infancy through school age to identify those at risk for atypical development. This practice is also recommended at any age thereafter, if social, learning, or behavioral concerns exist (Filipek et al., 2000). A screening can give physicians the opportunity to share a child's developmental strengths and challenges with parents. The screening also enables the physician to support and work with the family to help get that child on the correct developmental path. There are a variety of ways that physicians can integrate a developmental screening into a well visit.

If concerns are raised, proceed with guidelines 3 through 6.

3. *Refer to Early Intervention.* When a routine developmental screening shows that a referral is needed, the AAN parameter recommends referring the child to a local Early Intervention program or directly to a specialist (i.e., pediatric neurologist, psychiatrist, psychologist, or developmental pediatrician) for further developmental evaluation.

[4] The screening guidelines were compiled from the following source: Filipek et al. (2000). Practice parameter: Screening and diagnosis of autism. *Neurology, 55,* 468–479. This parameter is endorsed by the American Academy of Neurology and the American Academy of Pediatrics. The guidelines appear on the First Signs Web site and in the *First Signs Screening Kit for Pediatric Practitioners.*

4. *Conduct lead screening.* A child who mouths many objects, or puts non-food items in the mouth, may be at risk for lead poisoning. Because of the range of risks involved, lead screenings are routinely performed when children show signs of developmental delays or disorders. Such screening should be conducted immediately to rule out lead poisoning and, if detected, to minimize the negative effects of lead exposure. Additionally, the practitioner may want to refer the child for other medical screenings or subspecialty evaluations to rule out other conditions, because other factors can contribute to high lead levels.

5. *Perform formal audiological assessment.* The relationship between a child's hearing and communication or overall development is complex: A child who appears to have a developmental delay may, in fact, have a hearing impairment. A child with a hearing impairment that goes undiagnosed may experience resulting delays in development and communication. A child with a communication or developmental disorder may also have related issues with sensitivity to sound. When addressing concerns about a child, a developmental screening should be followed by formal audiological testing.

6. *Conduct autism screening.* If a routine developmental screening raises concerns, the AAN practice parameter recommends automatic follow-up with an autism screening. A parent can complete an autism screening tool in the physician's waiting room or with the assistance of a nurse, physician, or other professional in the examination room in less than 5 minutes.

7. *If additional concerns are raised: refer to formal diagnostic testing.* When an autism screening raises concerns—or for a child 18 months and younger, there are concerns raised from the history and observations—general pediatricians and family practitioners should refer the child to a pediatric neurologist, developmental pediatrician, child psychologist or psychiatrist for a formal diagnostic evaluation right away. This clinician should specialize in evaluating children with autism spectrum disorders.

Suspicions are eliminated systematically through the screening process by first using a broad-based developmental tool and then, if concerns persist, by narrowing the focus through an autism or Asperger screen. The recommended screening guidelines are critical for ensuring that young children stay on a healthy developmental path.

Parent Report and Physician Observation in the Screening Process

Accurate detection is heightened when practitioners systematically elicit parents' concerns through the routine use of screening tools (Glascoe,

1999). Parents have been shown to be accurate reporters and predictors of behavioral and developmental concerns, due to their constancy in their children's lives and to their tendency to compare their children to others (Glascoe). Additionally, pediatric physicians' observations enhance and strengthen the accuracy of screening tool measures. By listening carefully to parental concerns and by exercising a heightened index of suspicion in practice, pediatric physicians can use the developmental surveillance and screening processes to increase the chance of detection during very early development and to provide a clear compass for referral and treatment if a concern is flagged.

EFFECTIVE USE OF SCREENING TOOLS IN PRACTICE

Because there are no biological markers for autism, developmental and autism screening tools are necessary to identify these disorders. Screening tools are brief measures that distinguish children who are at risk for atypical development from those who are not. They range from effective questionnaires given to parents in waiting rooms to brief, but purposeful, give-and-take exchanges and observations during pediatric exams. Often, screening tools can help eliminate worries of developmental delays, by screening children *out* rather than *in* (First Signs, 2001b, 2003).[5] Screening tools have applications for physicians, health care providers, clinics, day-care center providers, schools, parents, and others who work with young children (First Signs, 2003).

There are a variety of ways for physicians to incorporate a developmental screening seamlessly into a well visit in under 10 minutes. A parent might fill out a screening form in the physician's waiting room; at home before a well visit; or with the assistance of a nurse, physician, or other professional in the examination room.

Although there are a number of screening tools currently available for use in practice, features and quality may vary greatly among them. Therefore, it is important for an individual physician or an entire practice to be discerning consumers when considering which screening tools fit their needs, work styles and training. These days, physicians need to manage their time as efficiently as possible; thus, they desire screening tools that are brief, flexible, inexpensive, and easy to use and score. Over and above administrative needs, a screening tool should be highly accurate when detecting developmental concerns. A high-quality screening tool should control costs

[5] Parts of this chapter have been derived from the First Signs video, *On the Spectrum: Children and Autism* (2001).

Must be statistically accurate and highly regarded among peers	*Must provide ease of use by physician or healthcare provider*	*Must be easy for parent or caregiver to use*	*Must be available at minimal expense for provider*
Highly validated	Can be administered at all well visits, 12 to 36 months	Caregiver can fill out in under 10 minutes	Low cost to maintain
Established tool on the market for at least 2 years	Brief to fill out (under 10 minutes)	Multiple choice	
Peer reviewed and published	Easy to tabulate (under 5 minutes)	Written for fourth- to sixth-grade reading level	
Recognized by a national organization	Parent report—No observation needed	Available in other languages	
Uses developmental milestones, if developmental screening tool, **OR** follows *DSM–IV*, if autism or Asperger screening tool	Easy to store, maintain, and explain	Alternative methods of administration	

FIG. 5.1. Properties of a high-quality screening tool (Adapted from First Signs, 2001a, 2003).

and increase care by flagging only those children who are truly in need of further evaluation, therefore avoiding under- and over-referral.

Screening tools vary with respect to targeted age range, accuracy, ease of use, completion time, languages available, and cost. To help physicians make sense of the myriad features found in validated screening tools, Figure 5.1 recommends attributes found in a high-quality screening tool (First Signs 2001a, 2003).

It should be noted that all screening tools have limitations and should not take the place of a good clinical history and observations. Conversely, clinical history and observations should not take the place of a good screening. Whenever developmental or autism screenings produce concerns, it is essential that physicians refer children for further evaluation, whether or not their own clinical observations agree with the outcome.

The field of developing screening tools for early identification of autism spectrum disorders is relatively new and uncharted territory. More research is needed to improve these efforts, particularly for children under 18 months of age and for milder variants of autism spectrum disorders. In this chapter, we present the best screening instruments currently available with the hope that researchers will continue to refine their methods to increase sensitivity of future autism screening tools. We look forward to the future identification

of genetic markers and related medical tests sensitive enough to detect and treat autism at its earliest stages.

PROPERTIES OF SCREENING TOOLS

There are several psychometric properties found in a high-quality screening tool: standardization, reliability, validity, accuracy, sensitivity, specificity, and positive predictive value (Glascoe, 1996, 1998). Although each psychometric property contributes to the statistical significance of a quality measure, it is the combination of these psychometric properties that determines a tool's overall value and effectiveness. The following reviews the properties that are incorporated into an effective screening tool (First Signs, 2001a, 2003).

Validation

Highly Validated

The overarching function of any type of screening tool is to sort those who most likely have true concerns from those who probably do not. To achieve this, it is critical for an effective screening tool to be *highly validated* and *accurate.*

A highly validated screening tool is one that (a) has been field tested and normed on large and diverse populations geographically and demographically (*standardized*), (b) the questions within it interrelate well and measure a well-defined construct (*internal consistency*), (c) different examiners rate subjects similarly using the same tool and over short periods of time (*interrater and test–retest reliability*), (d) the range of skills tested are developmentally appropriate (*content validity*), (e) the screening tool compares similarly to other screening tools on the market (*concurrent validity*), and, (f) most importantly, the screening tool is *accurate* (Glascoe, 1996, 1998).

Accuracy is the single most important psychometric property for any developmental or autism screening tool to have, particularly in the areas of sensitivity and specificity. *Sensitivity* illustrates how often a screening tool accurately identifies children suspected to be at risk for a developmental disorder or autism. *Specificity* illustrates how often a screening tool accurately rules out children *not* at risk (i.e., those who meet typical developmental milestones). A third key accuracy measure is *positive predictive value,* which indicates the percentage of children who are flagged as at risk by the screen and who later receive a confirming diagnosis.

In a high-quality screening tool, sensitivity and specificity should each exceed 70% to 80%, ideally reaching the 90th percentile for accuracy. Additionally, because the main goal of a screening tool is to identify the majority

of children at risk, sensitivity should be equal to or greater than specificity. Although high specificity keeps the cost of over-referral down and reduces unnecessary alarm to parents whose children are indeed not at risk, it is important to identify and treat every potential case of autism spectrum and other developmental disorders as early as possible, especially in light of the currently reported increases in prevalence rates.

Established Tool

A screening tool should have been in use for at least 2 years and widely distributed throughout the United States and even internationally. A consumer should look for supporting information that describes the test population and the length of time on the market.

Peer Reviewed

A screening tool that has been peer reviewed has been critiqued in a peer-reviewed medical or psychiatric journal or other professional publication. Peer review is a rigorous scientific process that inspects the methodology employed in developing and testing the tool. In essence, it is the final mark of approval by industry peers and colleagues.

Recognized by a National Organization

A screening tool typically gains prestige and credibility if it has been recognized by a national professional organization such as the AAP, the AAN, and other organizations of high caliber. Similar to peer review, a recommendation from a national professional organization typically occurs after rigorous review.

Developmental Screening Tools Should Use Developmental Milestones

Normative developmental milestones are the predominant gauges for tracking healthy development in early childhood. Developmental screening tools typically measure attainment of healthy developmental milestones, including social, emotional, cognitive, self-help, gross and fine motor, and communication and language.

Some developmental screening tools identify behavioral and regulatory concerns as their primary focus. Although these tools do not strictly follow developmental milestones, they are noteworthy, because many children with autism spectrum disorders exhibit difficulties in these key areas.

Broad-based developmental screening tools should be used routinely on all children as a *level one* primary population screen. Because developmental screens are not diagnostic, further evaluation by appropriate specialists is

required based on areas of concern highlighted by the screening tool's results.

Autism Screening Tools Should Meet DSM-IV Criteria for Autism

The *DSM-IV* is the abbreviated term for the *Diagnostic and Statistical Manual of Mental Disorders—Fourth Edition* (American Psychiatric Association [APA], 2000). It is the main diagnostic reference of mental health professionals in the United States. An autism screening tool should meet all three main areas of the *DSM-IV*'s definition of autism. The *DSM-IV* characterizes *autistic disorder* using three main criteria: qualitative impairment in social interaction; qualitative impairments in communication; and restricted, repetitive, and stereotyped patterns of behavior, interests, and activities.

Asperger Screening Tools Should Meet DSM-IV Criteria for Asperger Syndrome

Asperger syndrome screening tools should meet all six criteria outlined in the *DSM-IV*'s definition of Asperger syndrome. The *DSM-IV* characterizes *Asperger syndrome* using the following main criteria: qualitative impairment in social interaction, restricted, repetitive, and stereotyped patterns of behavior, interests, and activities; significant impairment in social, occupational, or other important areas of functioning; no clinically significant general delay in language; and no clinically significant delay in cognitive development (APA, 2000).

Ease of Use by Physician or Healthcare Provider

Can Be Administered at All Well Visits, Particularly Between 12 to 36 Months

Ideally, a screening tool should cover all well-visit ages from infancy through school age, but particularly from 12 to 36 months. If a screening tool can only be used at a certain age, it is advisable to have other tools on hand to address the other age groups. As a rule, developmental screening tools cover most well-visit ages.

Brief to Fill Out

If a physician or health care provider must deliver the screening tool as part of its design, it should not exceed 10 minutes to complete, due to time constraints imposed by insurance companies and other demands on health care providers. Most screening tools use *parent report* (a parent's

written response to a screening tool questionnaire) as the means to capture information, making *direct elicitation* (interview from a professional) necessary only if the parent is unable to answer the questions. Many tools can be completed in 5 minutes or less.

Easy to Tabulate

Tabulation should not exceed 5 minutes due to limits on healthcare providers' time. Many tools can be tabulated in less than 2 minutes. Some tools provide color-coded *cutoffs*, for greater visual ease in tabulation.

Parent Report—No Observation Needed

There are many advantages of parents answering screening tool questionnaires: (a) Less office time is required of the physician or healthcare provider, (b) responses can be mailed, (c) parents are full-time observers of their children's behavior, and (d) the exercise of thinking through responses to a developmental questionnaire increases a parent's accuracy. Parent report answers may be open-ended concerns or structured and prompted answers. Most importantly, research shows parents' concerns are highly accurate predictors of developmental and behavioral problems (Glascoe, 1999).

Easy to Store, Maintain, and Explain

It is preferable for a screening tool to be a standard size (8" × 11" or smaller) and not bulky or unwieldy to store. It should fit easily on a shelf or in a file cabinet and should be self-contained for minimal upkeep. Last, it should have brief, easy, accessible, and parent-friendly directions for health care providers to use and explain.

Ease of Use by Parent or Caregiver

Caregiver Can Fill Out in Under 10 Minutes

The time to complete a screening tool by a parent or caregiver in either a waiting room or at home should not exceed 10 minutes due to the many distractions that may prevent thorough completion. Many tools can be completed in 5 minutes or less.

Multiple Choice

Screening tool questions are phrased in a variety of different formats. Some capture an open-ended comment, some restrict an answer to a yes or no choice, some provide a range of multiple-choice options, and some include a combination of formats. A tool that has a brief, but flexible,

multiple range of choices is preferable (e.g., yes, no, sometimes, rarely, usually), because it addresses the time constraints on physicians and the need for parents to qualify their answers. Providing commentary with multiple choices has many of the benefits stated previously, but still demands extra time for interpretation. For the sake of simplicity, the screening tool should follow the same format for all its versions.

Written for Fourth- to Sixth-Grade Reading Levels

A screening tool should be simple enough for all parents and caregivers to understand and complete. Fourth- to sixth-grade reading levels include most people. A health care provider should assist those who cannot read the survey.

Available in Other Languages

Similar to reading level, access to a screening tool available in at least English and Spanish will ensure greater coverage of the whole population of parents. Additionally, other languages make the tool accessible nationally and internationally.

Alternative Methods of Administration

If reading level and language barriers prevent parents from filling out a questionnaire, the screening tool should be administered by a health care provider. For further flexibility and cost effectiveness, a preferred tool should be adaptable to multiple settings: the caregiver's home, a health care center waiting room, an early intervention center, or a physician's examination room.

Can Be Mailed

A screening tool that can be mailed allows for convenience and cost effectiveness. Disadvantages of mailing screening tools to caregivers are that they may be misplaced, delayed, or forgotten. Mailing a screening tool may save time, but it will reduce response.

Expense

A screening tool should require minimal upkeep and out-of-pocket expense in order to be used successfully and continuously by a health care provider. Often costs are contained to photocopying replacements only. Many screening tool publishers also sell manuals, informational handouts, related videos, and other supplements.

DEVELOPMENTAL, AUTISM, AND ASPERGER SCREENING TOOLS

The screening tools discussed in this chapter follow a continuum from broad developmental disabilities through the spectrum of more specific autism-related disorders and are classified into three main categories: developmental, autism, and Asperger syndrome or high-functioning autism. All are brief questionnaires that use parent report as their primary method of capturing information and can be used at appropriate well-visit appointments with a pediatric practitioner.

Developmental Screening Tools

Most developmental screening tools have a wide application with children of varying ages; allow flexibility to capture parent report with minimal assistance; ask relatively general, nonintimidating questions of parents; and coordinate with hallmark developmental milestones. Some developmental screening tools are specific to social and communication milestones, some are more focused on gross and fine motor skills, and still others deal specifically with behavior and temperament. Because of their broad use, developmental tools are not designed to screen specifically for autism and therefore require follow-up with an autism screening tool when the test raises concerns.

The following five developmental screening tools all meet high-quality standards. The Developmental Screening Tool Features Chart in Figure 5.2 provides qualitative information about each tool (see Appendix for contact information):

1. *Ages and Stages Questionnaires* (ASQ)™ (Bricker & Squires, 1999)
2. *Child Development Inventories* (CDIs; Ireton, 1992)[6,7]

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[6] The series of screening tools now known as the *Child Development Review* has been the *Child Development Inventories* (CDIs) until they were renamed recently; however, because of potential confusion between the CDR screening tool and the CDR series, we refer to the series of tools under their former name, CDIs, for the purposes of our review.

[7] Although there are several CDIs available, this review focuses primarily on the Infant Development Inventory (IDI), which covers birth to 18 months, because it most closely meets our selection criteria. Another CDI that we considered is the Child Development Review (CDR), which includes the Child Development Chart (CDC). It has been used in practice for many years and has many desirable features found in high-quality screening tools; however, to our knowledge, only one small validation study has been conducted for this screen for the 18- to 36-month age range with low sensitivity (68%) and very good specificity (88%). Therefore, although we generally support the use of the CDR, we cannot give it broad approval in this category in comparison with the other developmental tools. (Continued)

Developmental Screening Tools	ASQ	CDIs (IDI)	Infant-Toddler	PEDS	TABS
Psychometric Data					
Sample size	7700	2000+	2188	1137	1000+
# of years in use	1980	1972	1998	1997	1999
Inter-rater reliability	0.94		.72-.92	0.95	.81-.94
Test–retest reliability	0.94		0.88	0.88	.80-.90
Internal consistency	0.73		.87-.93	0.81	.88-.95
Content validity	yes	yes	yes	yes	yes
Concurrent validity	0.83	yes	.88	yes	yes
Sensitivity	72%	85-90%	84%	75-79%	72%
Specificity	86%	77-93%	72%	70-80%	83%
Ease of Use by Physician/Health Care Provider					
Well-visit ages	0 to 5 yrs.	0 to 6 yrs.	6-24 mos.	0 to 8 yrs.	11-71 mos.
Average # of minutes to tabulate	5	5	<2	3	<2
Parent report (P), observation (O) or both (B)	P	P	P	P	P
Ease of Use by Parent/Caregiver					
Average # of minutes to complete	10 to 15	5	5-10	5	<5
Reading grade level	4-6th	7th	6th	4-5th	3rd
Available in Spanish	Y	Y	N	Y	Y
Expense					
Anticipated costs to maintain questionnaires	Masters (paper or CD-Rom), labor + copies	Refills + products	Labor, copies + CD-ROM	Refills + products	Refills + products

FIG. 5.2. Developmental screening tool features chart. (Adapted from First Signs, 2000, 2001a).

3. *Infant-Toddler Checklist for Language and Communication* (Wetherby & Prizant, 2001)
4. *Parents Evaluation of Developmental Status* (PEDS; Glascoe, 1997)
5. *Temperament and Behavior Scales* (TABS; Bagnato, Neisworth, Salvia, & Hunt, 1999)[8]

Two popular screening tools that have been noted in the literature as less appropriate for developmental screening are the Denver-II (DDST-II, formerly the Denver Developmental Screening Test-Revised) (Frankenburg, Dodds, Archer, Shapiro, & Bresnick, 1992) and the Revised Denver Pre-Screening Developmental Questionnaire (R-DPDQ; Frankenburg, 1986).

The IDI was compared to the Bayley Mental Scales in two small-scale studies. The first, a study of 86 eight-month-olds (Creighton & Sauve, 1988), yielded good sensitivity at 85% and fair specificity at 77%. The second study (Creighton, Dewey & Sauve, 1997) on 252 eight-month-olds, including 48 low-birthweight infants, reported the IDI's accuracy as excellent at 90% sensitivity and 93% specificity. Based on the limited sizes of the studies, we include results for both in our Developmental Screening Tools Chart (Figure 5.2).

[8] The TABS is an alternative for physicians to use with children who may meet most developmental milestones but still present with behavioral and regulatory issues.

According to expert review of the medical literature, both lack sensitivity and specificity such that an alternative screening tool must be used for appropriate developmental screening at every well-child visit (Filipek et al., 1999).

Autism Screening Tools

Most autism screening tools are designed to detect autism spectrum disorders directly, concentrate on social and communication impairment in children 18 months of age and older, and focus on all three *DSM-IV* criteria for autism. They vary with respect to the validated age at which the tool should be administered, as well as to their accuracy and languages available. The youngest age for a validated autism screening tool is currently 18 months. Younger ages will need to rely on developmental screening tools to uncover concerns. Some require a health care provider to intervene directly in capturing data about the child when using an autism screen.

The following three autism screening tools all meet high-quality standards. The Autism Screening Tool Features Chart in Figure 5.3 provides qualitative information about each tool (see Appendix for contact information):

1. *Checklist for Autism in Toddlers* (CHAT; Baron-Cohen, Wheelwright, Cox, Baird, Charman, Swettenham et al., 2000)[9]
2. *Modified Checklist for Autism in Toddlers* (M-CHAT; Robins, Fein, Barton, & Green, 2001)
3. *Pervasive Developmental Disorder Screening Test* (PDDST-II Stage One; Siegel, in press)

Of the three autism screening tools listed, it should be noted that the CHAT has received positive media attention because of its brevity, its ability to flag children at risk as young as 18 months old from the general population, its use of practitioner observation, and its high positive predictive value. Although these attributes are highly desirable, most current pediatric guidelines voice concern over its low sensitivity, missing three fifths to four fifths of the children later identified as having autism (AAN, 2000; AAP, 2001). Also, although the PDDST-II Stage One has been in use the longest of the three, study data about the tool have not yet been formally published, but a manual is due to be released within the year. The M-CHAT is a promising expanded

[9] Because the CHAT was tested in England as a broad primary population screen, its reportedly low sensitivity was based on this application. Use of the CHAT as a secondary-level tool would most likely increase its sensitivity.

Autism Screening Tools	CHAT	M-CHAT	PDDST-II-I
Validation			
Sample size	16235	2051	943(518-ASD)
# of years in use	1992, 1996, 2000	1997	1985–2004
Inter-rater reliability			
Test–retest reliability			
Internal consistency		0.84	
Content validity	"high"		"high"
Concurrent validity	"high"		"high"
Sensitivity	20–38%	94%	92%
Specificity	98%	99%	91%
Positive predictive value	75%	57%	
Negative predictive value		99%	
Ease of Use by Physician/Health Care Provider			
Well-visit ages	18m	18 & 24m	0-36m
Average # of minutes to tabulate	<5	1	<5
Parent report (P), observation (O) or both (B)	B	P	P
Ease of Use by Parent/Caregiver			
Average # of minutes to complete	5-10	<10	5-10
Reading grade level	8th	4th	6th
Available in Spanish	Y	Y	Y
Expense			
Anticipated costs to maintain questionnaire	copies + labor	copies + labor	Refills + manual

FIG. 5.3. Autism screening tool features chart. (Adapted from First Signs, 2000, 2001a).

American version of the CHAT that has increased the CHAT's sensitivity from 38% to the M-CHAT's 94%. Its authors are still collecting data on the initial study and are awaiting longitudinal data for sensitivity and specificity after the subjects return for their 3.5-year well-child visit. Final outcomes are pending at the time of this writing.

Asperger Syndrome or High-Functioning Autism Screening Tools

Most Asperger syndrome or high-functioning autism (AS or HFA) screening tools are designed to detect these disorders in older children, further defining them from other autism spectrum disorders and other developmental disorders, such as mental retardation and language delay. These tools concentrate on social and behavioral impairment in children 4 years of age and older (up to adulthood), who usually develop without significant language delay. Qualitatively, these tools are quite different from the early-childhood screening tools, highlighting more social and conversational, as well as perseverative and behavioral, concerns.

Asperger-HFA Screening Tools	ASAS	SCQ	ASSQ
Validation			
Sample size	60	200	110+
# of years in use	1995	1999, 2004	1993, 1999
Interrater reliability	100%		66%
Test–retest reliability			95%
Internal consistency		0.90	
Content validity		0.84	.83-.91
Concurrent validity		0.71	0.95
Sensitivity	90%	85%	90-91%
Specificity	65%	75%	>90%
Positive predictive value		93%	95%
Negative predictive value			44%
Ease of Use by Physician/Health Care Provider			
Well-visit ages	age 5 and older	age 4 and older	age 7-16
Average # of minutes to tabulate	<5	<5	<5
Parent report (P), observation (O) or both (B)	P	P	Parent & teacher rpt
Ease of Use by Parent/Caregiver			
Average # of minutes to complete	<10	10-15	<10
Reading grade level	unknown	unknown	unknown
Available in Spanish	Y	Y	unknown
Expense			
Anticipated costs to maintain questionnaire	Copies + labor	Kit, refills + manual	Copies + labor

FIG. 5.4. Asperger syndrome and high-functioning autism screening tool features chart. (Adapted from First Signs, 2000, 2001a).

The following three Asperger screening tools meet high-quality standards. The Asperger Syndrome and High-Functioning Autism Screening Tool Features Chart in Figure 5.4 provides qualitative information about each tool (see Appendix for contact information):

1. *Australian Scale for Asperger Syndrome* (ASAS; Garnett & Attwood, 1994).
2. *Autism Spectrum Screening Questionnaire* (ASSQ; Ehlers, Gillberg, & Wing, 1999)
3. *Social Communication Questionnaire* (SCQ; Rutter, Lord, & Le Couteur, 2004), (formerly the Autism Screener Questionnaire [ASQ]; Berument, Rutter, Lord, Pickles, & Bailey, 1999)

THE REFERRAL PROCESS

When navigating the referral process, parents and physicians must work together to pursue the healthiest developmental outcome for a child at risk for an autism spectrum disorder. This includes referrals to specialists for diagnostic testing, referrals to Early Intervention for a free multidisciplinary

assessment if the child is under 3 years; and, if the child is over 3 years, a referral to the local school district for special services. Often, the wait to see a specialist can be up to a year long, so physicians and parents must act quickly.

Referral is not one step; it is an integrated process that requires persistence on the part of physicians and parents. When navigating the maze of referrals, waiting lists, insurance forms, testing, and specialists, many parents struggle. Parents must overcome both emotional and practical difficulties as they move forward with the referral process. Accordingly, it is imperative for physicians to work with parents as active participants throughout the referral process.

Early diagnosis and intervention will bring the best results for a child at risk of a developmental disability, but without assistance, some families may face a delay in receiving services. At the next office visit, physicians might review:

1. Did the physician or the child's parent(s) make an intake appointment with Early Intervention?
2. Was a diagnostic referral made to a specialist?
3. Are there referrals that might be made through the family's insurance plan?
4. What help does the family need?
5. And, most importantly, how is the family doing?

After a physician confirms the presence of a developmental delay or disorder, parents have to contend with a range of emotions: grief, disbelief, anger, hope, fear. Coming to terms with a child's developmental delay or disorder can be a lengthy process. Although each parent responds differently, many parents recall that the first steps toward self-education and action proved crucial not only for their child's well-being but also for their own. The only magical formula for a child's best outcome is an active and involved parent. Parents do not need a degree in psychology, and they should not hesitate to ask their child's physician for help. Moreover, they will need to lean on family and friends. Beyond love and acceptance, creativity and persistence are invaluable tools.

In speaking to parents of children diagnosed with autism and other developmental disabilities, one theme is clear: Parents must act quickly. The longer parents delay getting a diagnosis, the longer they must wait to get the appropriate intervention. Consequently, the more difficult it can be to help a child reach his or her greatest potential.

Specialists can play a key role in the diagnosis of, and treatment for, autism spectrum disorders. Parents and physicians should seek input from specialists as part of a *team approach* that draws on special expertise and is geared to the unique needs of each child. In a medical practice, physicians routinely

refer children to specialists because the nature or severity of a condition requires special expertise. Similarly, many children with developmental disorders benefit from referrals to specialists with experience in the diagnosis and treatment of these conditions. Each developmental disorder has multiple, and variable, impacts on a child. These impacts are best assessed and addressed by a range of clinicians and caregivers, working together in a team approach. This approach, also known as a *multidisciplinary approach,* is built on the core concept that each participant, whether parent, physician, or other clinician, adds a new dimension of understanding and expertise.

In the case of children with autism spectrum disorders, the Practice Parameter for the Screening and Diagnosis of Autism (Filipek et al., 2000) recommends a comprehensive multidisciplinary approach, which can include one or more of the following professionals: psychologists, neurologists, pediatricians, child psychiatrists, speech-language pathologists, occupational therapists, physical therapists, audiologists, educators, and special educators. The composition of the team is contingent on the presenting needs of the child. Through observation, evaluation, and study, physicians and parents can work together to identify the unique needs of each child. Accordingly, any specialists involved and treatments implemented should be determined by those unique needs.

DIAGNOSTIC TESTING

Diagnostic tests and other clinical evaluations help to determine the nature, scope, and intensity of each child's unique abilities and deficits. As recommended in the Practice Parameter for the Screening and Diagnosis of Autism (Filipek et al., 2000), the diagnostic evaluation should be conducted by a clinician (i.e., pediatric neurologist, developmental pediatrician, child psychologist, or child psychiatrist) with extensive experience—or one who specializes in—autism spectrum disorders. Diagnostic testing for autism spectrum disorders is not a one-time procedure; it is a complex process.

The following three autism diagnostic assessment tools all meet high-quality standards:

1. *Childhood Autism Rating Scale* (CARS; Schopler, Reichler, & Renner, 1986). CARS is a 15-item behavior rating scale, based on direct observation, parent report, and other records. CARS can help a clinician identify whether a child over 2 years of age is on the autism spectrum and, using a 7-point scale, can distinguish the degree to which the child's behavior deviates from that of a typically developing child of the same age.
2. *Autism Diagnostic Interview-Revised* (ADI-R; Rutter, LeCouteur, & Lord, 2004). The ADI-R is a clinical diagnostic tool for assessing autism

spectrum disorders in children and adults with mental ages 24 months and above. The instrument focuses on behavior in three main areas: qualities of reciprocal social interaction; communication and language; and restricted and repetitive, stereotyped interests and behaviors. The ADI-R can help to differentiate autism from other disorders (e.g., Rett syndrome, fragile X, disintegrative disorders) in very young children, and to differentiate between deviance and delay.

3. *Autism Diagnostic Observation Scale* (ADOS; Lord, Rutter, DiLavore, & Risi, 2001). ADOS is a semistructured assessment tool consisting of a variety of activities that allow clinicians to observe any communication, social interaction, or play behaviors that are consistent with the diagnosis of autism spectrum disorders. ADOS can be used to evaluate almost anyone suspected of having autism—from toddlers to adults, including those with no speech and those who are verbally fluent.

CONCLUSION

Physicians play a pivotal role in promoting positive outcomes for children with autism and other developmental disorders. This role includes monitoring a child's development, conducting routine developmental surveillance—including performing a developmental screening at every well visit—and choosing measures that are highly validated and sensitive enough to detect atypical development in young children. It is critical that the physician act immediately when a developmental concern is raised and refer the child to Early Intervention and pediatric specialist(s) for diagnostic testing and treatment. Parents and pediatric physicians must work in partnership to ensure that all children grow and develop to their full potential. Physicians can have significant impact on the outcome of a child at risk for autism or other developmental disorders. The earlier the diagnosis, the better the prognosis for the child.

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APPENDIX

Contact Information for Obtaining Screening Tools and Diagnostic Assessments

Ages and Stages Questionnaire (ASQ), Paul H. Brookes Publishing Company, Inc., P.O. Box 10624, Baltimore, MD, 21285, 1-800-638-3775, www.brookespublishing.com/asq

Australian Scale for Asperger Syndrome (ASAS), In *Asperger's Syndrome: A guide for parents and professionals.* Jessica Kingley Publishers, 116. Pentonville Road, London NI 9JB, 44(020)7833 2307, http://www.jkp.com.

Autism Diagnostic Interview-Revised (ADI-R), Western Psychological Services, 12031 Wilshire Blvd., Los Angeles, CA 90025-1251, 1-800-648-8857, www.wpspublish.com

Autism Diagnostic Observation Schedule (ADOS), Western Psychological Services, 12031 Wilshire Blvd., Los Angeles, CA 90025-1251, 1-800-648-8857, www.wpspublish.com

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Childhood Autism Rating Scale (CARS), Western Psychological Services, 12031 Wilshire Blvd., Los Angeles, CA 90025-1251, 1-800-648-8857, www.wpspublish.com

Child Development Review, Behavior Science Systems, Inc., P.O. Box 19512, Minneapolis, MN, 55419-9998, 1-612-850-8700, http://www.childdevrev.com

Infant-Toddler Checklist for Language and Communication, Paul H. Brookes Publishing, Inc., P.O. Box 10624, Baltimore, MD, 21285, 1-800-638-3775, www.brookespublishing.com

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Parents Evaluation of Developmental Status (PEDS), Ellsworth & Vandermeer Press, Ltd., P.O. Box 68164, Nashville, TN 37206, 1-888-729-1697, http://www.pedstest.com/test/index.html

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Chapter 6

The Challenge of Early Intensive Intervention

Jack Scott
Florida Atlantic University

Wanda L. Baldwin
St. Mary's Hospital West Palm Beach, Florida

EARLY INTERVENTION FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS

Early intervention for children with autism spectrum disorders (ASD) represents one of the most exciting areas within disability. It is exciting in that so much is now known that can make major differences in the early life of a child with autism. These differences then have the chance of offering compounding benefits throughout the life span. Better assessment processes, including far greater use of screening tools, wider availability of services, and more knowledgeable service providers, persons who actually know about autism and helping families of children with autism, all contribute to the more positive picture. It is exciting because school programs are increasingly inclusive while being autism-sensitive, therein providing necessary services in less restrictive environments. Inclusion practices, coupled with better transition services, allow individuals with autism to achieve at levels that had not been considered possible until recently. It is also exciting in that parents tend to be very involved in helping their child and eager to learn how to teach skills and arrange environments. The federal Part C early intervention programs for children ages 0 to 3 years and their families help to bring resources to this eagerness and provide a broad array of intervention options to families.

What do we mean when we refer to early intervention for children with ASD? Intervention refers to a plan of services and supports designed to help the child overcome some or all of their neurobiological challenges. The age range of children begins at birth and will typically go until the child reaches kindergarten age. This is usually 6 years of age. Some children, depending on their needs, may be considered appropriately served under an early intervention program model until they are somewhat older but rarely beyond the age of 7 years.

This chapter deals with effective early intervention for young children with autism. It begins with a review of early intervention and then considers some of the features of autism within the child and within the family that influence early intervention. Next, is a consideration of the key findings of major studies of effective early intervention programs for autism. The common elements of these studies are then examined. Then some systems for supporting early intervention are reviewed, including the federal Part C programs, parent-directed support agencies, and parent home programs. The chapter also discusses some issues relating to home programs. Finally, critical issues in the area of early intervention for autism and recommendations for future progress are presented.

EARLY INTERVENTION

For persons involved in intervention for children with autism, it is important to remember that children with autism are more similar than different from other children. Autism intervention, too, is more similar than different from intervention for any child with a disability or special need.

History of Early Intervention

Early intervention for children with disabilities is a relatively recent innovation and federal legislation has done much to foster it. The Economic Opportunity Act of 1964 (PL 88-452) was to lead to Head Start, which, although initially intended to help children whose families faced economic disadvantage, was to play a role in early intervention. It set several early key intervention elements in place including community control of programs, parents as decision makers, and the need for coordination of needed services (Guralnick, 1997). The beginning of significant federal attention to early intervention can be traced to the passage of the Handicapped Children's Early Education Act of 1968 (PL 90-538). With this act, training for professionals and demonstration and dissemination projects were begun in earnest. Public law 94-142 in 1975 was critical because it confirmed the

national educational commitment to all children with disabilities. Most significant of all, however, were the Handicapped Act Amendments of 1986 or PL 99-457. These established the framework for states to form comprehensive early intervention programs for all infants and toddlers with disabilities. The legislation states:

> "It is therefore the policy of the United Sates to provide financial assistance to States- "(1) to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families..." (Section 631, IDEA, 1997)

The reauthorizations since that time (PL 102-119 and 105-17) have strengthened what was established with PL 99-457. The federal legislation is, in many ways, the formal expression of a societal trend to help very young children with disabilities and their families. This would include an appreciation for the quality of the parent–child relationship, the quality of the young child's daily environment, and an appreciation of the interaction of biological risk with social and environmental factors. Each of these federal pieces of legislation requires those in the systems of providing intervention resources to see families as *planners* and *recipients* of services. Specifically relating to Part C, the law emphasizes the belief in *natural environments* or those "settings that are natural for the child's age peers as the primary resource for child development" (Gilkerson & Stott, 2000, p. 457).

Early Intervention Research

The research conducted prior to 1986 has been referred to as "first-generation" research by Guralnick (1997) with research conducted after 1986 to about 1997 as second-generation research. Some of this early research offers powerful and highly autism-relevant findings. Three major reviews of research (Casto & Mastropierie, 1986; Guralnick & Bennet, 1987; Shonkoff & Hauser-Cram, 1987) established that early intervention was effective. Shonkoff and Hauser-Cram (1987) relied on meta-analyses of 31 studies of services for children younger than 3 years of age. They found strong positive effects overall, with a mean effect of 0.62 (range of −0.94 to 2.08) or as the authors stated "the best available studies of early intervention for disabled children younger than 3 years of age demonstrate a 0.62 SD superiority in performance for children receiving services compared with a contrast or control study" (p. 652). This moderate degree of effect was the general result. Children with developmental *delays* achieved 0.70 *SD* and heterogeneously labeled children achieved 0.94 *SD*. The features of the programs that were associated with the largest effects are interesting

in relation to autism. When the extent of curriculum structure was high (as is found in many recent interventions for young children with autism) the effect was 0.92 *SD* in contrast to 0.59 *SD* for low structure. When the level of planned parent involvement was "extensive" the effect was 0.70 *SD* in contrast to only 0.30 *SD* for limited parent involvement. Finally, when the nature of parent involvement was considered, in programs that brought the parent and the child together for intervention, the effect was 0.74 *SD* and only 0.44 *SD* when the parents and children were targeted separately. It is important to recall that Shonkoff and Hauser-Cram's study was not focused in any way on autism. But this study, as well as the similar findings of Guralnick and Bennet (1987) and Casto and Mastropieri (1986), helped provide strong empirical support for the notion that carefully planned intervention could make a very significant difference in the lives of young children. It is obvious that the program factors associated with the largest effects have been standard aspects of comprehensive early intervention for children with autism for many years. The results of these pioneering studies provided confirmation to what was beginning to become apparent in the field of autism: Early and intensive intervention with high levels of structure and high levels of planned parent involvement can make very big differences.

The Role of Parents in Early Intervention

The role of parents in early intervention has changed remarkably within the life span of many veteran interventionists. Harbin (1993), using forms of family involvement described by Simeonsson and Bailey (1990), offers five stages for the development of parent involvement.

1. 1900–1950s	Parents relinquished care of their child to large institutions
2. 1950–1960s	Parents as bystanders and observers of professionals
3. Early 1970s	Parents actively encouraged to become involved in intervention
4. Mid-1970s	Parents seen as teachers and education decision makers
5. 1980s–present	Families as planners and recipients of services

These changing stages supported the change in locus of service from institutions to the home and the parents' role from one of virtually no involvement to that of being central to and the driving force of intervention efforts. Bronfenbrenner (1979) was influential in forging the view that development occurs within a series of nested environmental frameworks with the *ecostructure* of the family forming the primary environment for the very young child.

Dunlap and Fox (1996) write that, "In an ecological perspective, appropriate practices are ones that consider the whole unit of the child within the family when deciding on the nature of intervention.... [this perspective] provides a framework for understanding contextual issues that may affect an aspect of early intervention..." (p. 33). This ecological view is now paramount in autism intervention.

Unique Features of ASD in Relation to Early Intervention

Certainly young children with autism share many characteristics with young children with other disabilities. But they have differences that are unique to the autism spectrum (Asperger, 1944; Courchesne, 1991; Frith, 1991; Kanner, 1943; Lotter, 1967; Mundy & Sigman, 1989; Ornitz & Ritvo, 1968; Prizant & Duchan, 1981; Strain & Fox, 1981; Szatmari, 1992; Volkmar, 1996; Wing & Gould, 1979). These differences must be taken into consideration for any intervention effort that seeks to optimize the outcomes for the child and family. It has been suggested that it is these very differences that may enable young children with autism to achieve the relatively high degree of progress that many of them appear to make in highly structured and intensive programs. Rogers (1998) suggests that one reason for this progress may be the deep similarities among children with autism. Rogers emphasizes the neuropsychological similarities including intersubjectivity; imitation; and problems with executive functioning, emotional capacity, and sensory functioning. These core and widely shared deficits may, in fact, have sharpened the quest for maximally effective interventions and may hold the key to further refinement of effective intervention. In the future, the interaction of these deficits with family factors may permit far greater targeting of intervention efforts and allow for greater efficiency in intervention.

Social Reciprocity, Joint Attention, and Related Social–Emotional Factors and Early Learning

Children with autism generally have deficits in emotional expression and affect. Kanner (1943) noted, "that these children have come into the world with innate inability to form the usual, biologically provided affective contact with people, just as other children come into the world with innate physical or intellectual handicaps.... we seem to have a pure-culture example of inborn autistic disturbances of affective contact" (p. 50). Parents express love and affection for their child and are warmed by the return of affection from their child. This is usually blunted with children with autism. Although parents can learn to adjust to this lack of responsiveness, it emerges as a prominent feature in any list of early parent concerns. Mundy and Gomes (1998) note that the child with autism characteristically will not attempt

to share their interest or joy in an exciting object with parents. This deficit in *joint attention* holds profound impact for early bonding with the child's parents. The normal reinforcer for many early learning experiences is the joy of the parents, which they then reflect back to the child. This typically motivates the young child and serves as the most natural reinforcer for very early development and learning. Joint attention is but one element of social reciprocity. Other elements in the context of the young child include failure to greet parents, lack of interest in other children, atypical use of others' bodies, and failure to attempt to direct visual attention of others. These deficits make early learning far more complex. Parents must learn to adjust to far lower levels of affect and overall reciprocity from the child and recognize that their joy may not serve a motivational function for the child.

But parents must play with their children and do so thoughtfully. Siller and Sigman (2002) conducted a study in which they analyzed the degree to which the parents synchronized their behavior with that of the child. They determined that the parents who demonstrated a higher capacity to synchronize their behavior with that of the child had children who later demonstrated higher levels of joint attention and language. This study provides evidence that parent sensitivity to the behavior and especially the social–attention capacities of the child are crucial for the child to overcome biologically mediated deficits in these realms.

Deficits in establishing intersubjectivity may portend even more serious consequences for the young child with autism (Hobson, 1993). It may be that in some cases infants and even young children with autism fail to develop a concept of other persons, including their parents, as individuals, with separate experience and identity. The deficit is perhaps not just one of social recognition but fundamentally one of recognizing that other persons are persons. Theory of Mind (Baron-Cohen, 1995) would reflect a subset of this view with a focus on the child having an awareness of the mental state of the other person. Intersubjectivity, however, is truly basic to the development of the child as they learn who they are and learn that other people are separate and independent and, in the case of parents, caring and compassionate. Parents' natural play behavior with their children help to socialize the child and foster an early sense of identity. Many developmental activities parents are encouraged to use for early intervention are based on the notion that the child will find it rewarding to interact with the parents. For the very young child with autism, this is often not the case. These deficits will influence virtually all aspects of the parent–child relationship.

Pervasiveness of the Disorder and Impact on Family Life

Autism is considered a pervasive developmental disorder. This suggests that the impact of the disorder affects virtually all aspects of the individual's life. But autism as a pervasive disorder can have an expanded meaning with

the pervasive impacts touching all members of the family as well. Consider just these six ways that autism may have a pervasive impact on a family.

1. When the young child with autism displays some unusual behavior, some member of the community might see this behavior as the result of the parents' style of parenting. For example, the child's lack of eye contact may be seen as a rude behavior. Vigorous resistance to a parent request may be seen as a parental failure to set limits or to have gained control of their child.
2. The child may have sensitively to sound or stimuli in the environment that makes it difficult for them to become centered or comfortable in that environment. Parents are often on high alert for good and bad environments for their child.
3. Sleep problems, as just one example, can have a broad impact on family life. Schreck and Mulick (2000) found a high rate of parent-reported sleep problems in children with autism and noted that the quality of the child's sleep was frequently problematic. A child who has trouble sleeping will likely have one or more parents whose sleep is frequently interrupted.
4. The child may tolerate a limited array of foods or textures of foods. Feeding children, typically a source of great pleasure for parents, can be a constant source of social embarrassment or it can result in a heightened sense of inadequacy.
5. Appropriate child care may not be available, making it difficult for parents to return to work or even go out for an evening together. This can impact a family financially and put multiple stresses on a marriage.
6. The child's limited social and play skills can make it more difficult for parents to receive community support. Sunday school, Mommy and Me, play dates, all become more difficult emotionally for the parent due to the child's limitations. Parents, in some cases, may become more socially withdrawn.

Of course, many more examples could be cited. Most parents of children with autism face a very difficult task with the routine activities of daily life. Adding demands for parents to actively participate in early intervention can seem burdensome.

Risk for the Development of Problem Behaviors

Children with autism are at elevated risk for developing patterns of behavior that create problems for their parents and challenges to professionals who may seek to help them and their families. Until the mid-1980s, many professionals may have believed problem behavior was a more or less inevitable companion to autism. But as the communicative nature of most, if not all, problem behavior became obvious (Carr et al., 1994; Carr & Durand,

1985; Iwata, Dorsey, Slifer, Bauman, & Richman, 1982), communication-enhancing strategies such as functional communication training (FCT) became commonplace. In other words, there is now a recognition that problem behavior is an effort on the part of the child with autism to say something—with words or vocalizations or by behaviors if needed. These nontraditional communications need not be socially appropriate to serve useful functions for the child. If they get *results* they will probably occur more often in the future. FCT seeks to provide the child with better ways to communicate, limit the usefulness of problematic efforts to communicate (usually by coaching adults to ignore them and having adults prompt use of desired forms of communication), and enhance the responsiveness of family members and others to the newly learned more appropriate forms of communication. Functional analysis and functional assessments permitted professionals to understand the likely function or functions of problem behavior (Horner & Carr, 1997; Iwata et al., 1982). The positive behavioral support (PBS) tradition now offers a rich source of family-friendly approaches well suited to help if a young child with autism does begin to display problem behavior (Horner, Carr, Strain, Todd, & Reed, 2002). Mullen and Frea (1995) offer specific PBS techniques for professionals seeking to help families of individuals with autism that rely on the establishment of a caring relationship and training in parent-relevant PBS skills. Parents in this model become empowered as "functional assessors" (p. 184) and learn skills that will be valuable in helping reduce or eliminate problem behaviors for their child.

With early intervention (especially early intervention that features good parent training and education), along with the development of positive responses to challenging behaviors, the likelihood of severe problem behaviors can be reduced in most cases (Horner et al., 2002). Parents face challenges in this regard, however. Allen and Warzak (2000) address the subject of adherence to behavioral program treatment guidelines and note that families face contingencies that work against faithful application of the right behavioral response. The authors give this example:

> A parent may have been instructed to ignore a child's tantrum, but in public, the social community is disapproving of tantrums. In a public context, the child's silence is established as a reinforcer, and any parental behavioral that quickly brings about that response is reinforced. Unfortunately, this typically involves either an aversive control procedure whereby the tantrum is punished or negative reinforcement in which the parent "gives in" by meeting whatever demand evoked the tantrum. (p. 377)

At one level, it may be efficient and completely understandable for parents to explain problem behaviors being displayed by their child as simply a feature

of autism. With increased sophistication of intervention and improvement in parent and family education, we should expect to see far less problem behaviors as children who had good early intervention grow older.

Parent Urgency to Begin Treatment: The Window of Opportunity Problem

Some parents of children with autism, when receiving a diagnosis of autism and initially learning about the potential for very early intervention for children with autism, seek to begin intervention immediately. This is not surprising in light of research on early neural development and the suggestion that there may be a *window of opportunity*. Research on the neurological processes involved give rise to increased hope for early intervention efforts, but understandable confusion as to the size of this window can be detrimental to sound intervention planning. Nelson (2000) notes some factors relating to the complexity of the timing of intervention:

> This process... referred to as neural plasticity, is often bounded by time; that is, there may be a window of opportunity, or critical period, for altering neural function. However, it will also be apparent that critical periods often interact with different neural systems, such that some neural system remain open to modification longer than others. Moreover, there is evidence that critical periods and neural systems may interact at yet a third level, that of the individual. Thus, there may be individual differences in both the timing and the extent to which neural system can be modified by experience. (p. 204)

In this light, it may be more appropriate to speak of a *zone of opportunity* rather than of a window of opportunity with the suggestion of being on one side or the other of the window that may be brought to mind by parents or professionals. For children with autism, beginning early is desirable, but a rush to establish a program immediately is not prudent.

Fenske, Zalenski, Krantz, and McClannahan (1985) examined intensive intervention program benefits for children who began prior to 60 months of age, early in contrast to those who started after 60 months of age. Early entry was "found to be strongly related to positive treatment outcome...." (p. 49). In this study, mean age of diagnosis was 40.8 months and age of program entry was 48.9 months or 8.1 months after diagnosis. Here we see an 8.1-month time period that may have gone toward planning, further assessments, parent reflection, and training without apparent loss of intervention impact for the child.

Although moving promptly is a good idea, some parents will seek an immediate commencement to intervention. This is likely to be disadvantageous in at least three ways. First, beginning any important undertaking in haste will inevitably be wasteful in terms of resources and mental and emotional

energies. Planning takes time. Second, and closely related to the first issue, is that rushing to intervention will not comport with the timelines of even the most efficient and prompt services provider. Part C, preschool personnel and even private providers must proceed in a deliberate manner to schedule assessment, consider plans based on those assessments, and organize resources. The problem here is that should parents insist on immediate action, relationships may be strained from the start and they may never become truly productive. Finally, allowing any one child to be given *fast-track* treatment will inevitably come at the expense of other children and families. No one really benefits from such a rush. Parents should be informed that it will take a period of time to establish a suitable program of intervention services. If the parents intend to pursue a specific intervention approach, they should take time to study the merits and limitations of the approach; obtain training in that approach if practical; and talk with several families that have experience, both good and bad, with that approach; and in these ways be diligent in their review of treatment options. Fortunately, autism, unlike some disorders, is not progressive and degenerative. A planning phase of several weeks or even a month should be expected and, based on the available data, will not reduce the overall benefit of a comprehensive intervention program. This planning phase is, in fact, the first step in early intervention, and parents should be encouraged to be patient and to use this time wisely.

Special Needs of the Family and Early Intervention in Autism

Availability of Supports for the Family

The word *supports* is used so often in relation to parents in the context of early intervention that it may help to give this term careful consideration. Supports will usually refer to the help parents need, when they need it, in ways that they—the parents—find useful. It may involve some direct work by the interventionists with the child, but it is different from direct intervention or the delivery of treatment to the child. Dunlap and Fox (1996) list six services that must be considered in any set of comprehensive supports for families. They note that this is not an exhaustive list nor is it intended to be definitive; rather, it is illustrative of the types of services many families will require.

1. Information-about disabilities, the specific child's disability, legal and procedural rights, services and service options, and other resources
2. Education and training in positive behavioral support strategies, child development and parenting, and advocacy

3. Planning and assistance with person-centered planning, transitions, and finances
4. Service coordination (case management), including identification of appropriate services, brokering, arranging for transportation, and other logistical support
5. Social and emotional support with counseling, support groups, parent-to-parent support, sibling support, and friendship
6. Respite care both in home and out of home, child care, extended respite, and crisis relief (p. 43).

Dunlap and Fox make an excellent observation relating to family needs, "The diversity of families suggests that there is a similar diversity in the range of supports that families might require" (p. 42).

Reacting to the Diagnosis

Family members react to a diagnosis of autism in different ways. And even long before there is a formal diagnosis, parents will typically suspect that their child in not developing typically. This may not be surprising in that the average age of initial diagnosis has been reported as between 3.5 and 4 years of age (Siegel, Pliner, Eschler, & Elliot, 1988). Werner, Dawson, Osterling, and Dinno (2000), in an extension of a previous study on early recognition of signs of autism (Osterling & Dawson, 1994), found that parent's home videotapes provided early evidence of behavioral atypicalities. This is especially true when late-onset autism was considered separately. Werner et al. reported that "this study suggests that differences between infants with early onset autism spectrum disorder and typical development can be detected at 8–10 months of age" (p. 161). They go on to note that the strongest finding to emerge from their study was that the young children with autism were "much less likely to orient when their name was called . . . " (p. 161). This aligns with parents reporting that they initially thought their child might have a hearing impairment and other suspicions that something was wrong but that the parents did not know what it was. With autism, both an early onset and a later onset, typically coupled with developmental regression, have been well noted.

Davidovitch, Glick, Holtzman, Tirosh, and Safir (2000) studied maternal perceptions in both early- and late-onset autism. The age at which mothers first noted concerns for development was reported as approximately 18 months for the nonregressed sample and 33.5 months for the regressed sample of children. Important from an early intervention standpoint was the lag time between problem recognition and definitive diagnosis. For the early-onset group, the time was 12.2 months, whereas it was only 6.8 months for the regressed group. Additionally, these researchers noted that a higher proportion of the mothers of children in the regressed group

reported guilt feelings. This could be attributed to the obvious and dramatic unexplainable regression of their child and their painful inability to do anything to stop it. In any case, Davidovitch et al. note that those seeking to help parents of children with later onset should be prepared to address these feelings of guilt.

Siegel (1996) has written about the difficulty, as a clinician, of telling parents that their child may have autism. "Some parents intuitively understand their child is autistic before the doctor actually uses the word 'autism.' Some parents need to hear the diagnosis of autism from several different sources before it can be fully accepted. Sometimes parents don't tell me that their child's been diagnosed autistic before, or don't tell me the previous diagnosis—just to be sure that my opinion is independent. Parents come for second, third, and fourth opinions or however many their insurance policy will tolerate" (p. 123). Siegel's advice to parents closely follows the subject of this chapter.

> My strongly held opinion is that starting with treatment is the best way to begin to work through the acceptance of the diagnosis. I see treatment planning as the single most powerful resource in coping with a diagnosis of autism. The sooner the treatment begins, the sooner there will be some positive change in the child and the parents can begin to see that the child's situation is not hopeless. (p. 124).

There are, indeed, sound reasons for hopefulness on the part of the family in response to a diagnosis of autism when they are prepared to quickly begin planning and then able to provide a comprehensive early intervention program for their child.

Abundance and Range of Treatment Options and Conflicting Claims

The range of treatment options coupled with conflicting and often unsubstantiated claims presents a dilemma for both parents and professionals. This chapter focuses on approaches that are supported by some effectiveness data with strong theoretical and practical underpinnings. But the broader world of autism options includes many "treatments" for which extreme claims are made with no evidence, perhaps apart from testimonials, in support of these claims (Scott, Clark, & Brady, 2000). Complicating matters further is the abundance of information to be found on the Internet and in other sources. Consider that in June 2003 a Google Internet search on the term *autism* yielded 1,060,000 hits; *autism treatment*, 216,000 hits; and *autism therapy*, 195,000 hits. Never in history has so much information, and at the same time misinformation, been easily available to families.

Allergy therapies for autism	Mercury chelation therapy
Anitfungal medication	Melatonin
Anti yeast therapy	Music Therapy
Applied behavioral analysis	Natural Language Paradigm
Auditory integration training (AIT)	Occupational Therapy
Casein and /or gluten free diet	Picture Exchange Communication System (PECS)
Cognitive approaches	Pivotal Response Training (PRT)
Craniosacral Therapy	Play Therapy
Discrete trial training" (DTT))	Precision Teaching
Dimethylglycine (DMG)	Prism Lenses
Dimethyl Amino Ethanol (DMAE)	Psychology Psychotherapy
Dolphin therapy	Psychodynamic Therapy/Psycho-dynamic Therapy
Doman/ Delacato Method	Reiki massage (body therapy)
Drug therapy: i.e., Adderall, Anafranil, Clomipramine, Clonazepam, Clonidine, Desipramine, Desyrel, Dexadrine, Dilantin, Dipiperon, Haldol, Imipramine, Lithium, Luvox, Naltrexone, Nizoral, Piracetam, Prozac, Ritalin, Prednisone, Risperdol, Tegretol, Trexan, Zoloft	SSRI "Selective Serotonin Reuptake Inhibitor"
Eliminating dietary yeast	Secretin infusion
EPD (Enzyme Potentiated Desensitization)	Sensory Integration Therapy
Epsom Salt Baths	Social skills training
Floortime	Social stories
Folic Acid	Son-Rise Program
Ginko Bilboa supplements	Speech-Language Therapy
Higashi (Daily Life Therapy)	The Squeeze Machine
Holding Therapy	TEACCH-Treatment and Education of Autistic and related Communication Handicapped Children
Homeopathy	Tomatis Method
Irlen Lenses	Therapy Dogs
Intravenous Immunoglobulin	Verbal Behavior
Lovaas Method	Vision Integration Therapy
Magnet Therapy	Vitamin/Mineral Therapy
	Vitamin B6
	MST (Multiple subpial transactions) Surgery

FIG. 6.1. A partial listing of therapies that have been offered or promoted to offer benefits for young children with autism.

Figure 6.1 provides a partial listing of treatments or approaches offered to improve the lives of persons with autism. It is unfortunate that some families (and professionals) failed to heed common sense and rushed in to embrace some of these lesser or noneffective approaches. *The Report of the Recommendations—Autism/Pervasive Developmental Disorders: Assessment and Intervention for Young Children (Age 0–3 years)*, sponsored by the New York State Department of Health, Early Intervention Program (1999), addresses a wide range of treatments and provides cautions for their use. The report[1] goes so far as to *not* recommend and detail the possible adverse outcomes for many commonly used approaches. Smith (1996) offers a critical assessment of the value of many treatments for autism. Green (1996a) provides a model

[1] This report is available on the Internet at www.health.state.ny.us/nysdoh/eip/index.htm.

by which parents can judge claims for intervention effectiveness that relies on scientific principles. Green suggests that the nature of the evidence be examined, including the degree to which the supporters of a claim have relied on subjective in contrast to objective evidence. Park (2000), in his book *Voodoo Science: The Road From Foolishness to Fraud,* further explores the general process by which some well-meaning persons are unintentionally drawn to promote pseudoscientific or even antiscientific treatments. The process, according to Park, rarely begins with an attempt to deceive, but rather appears to be the result of a failure to respond to contrary evidence. The failure to fully appreciate evidence or data is one of the hallmarks of the treatments that should be avoided. The rush of enthusiasm that accompanied the practice of Facilitated Communication can be offered as a fairly recent example of this phenomenon in autism. The final portion of this chapter contains guidelines for families and professionals to use in considering any intervention or treatment. The short version of these guidelines suggests that parents heed the folk wisdom that says that if something seems to be too good to be true, it probably isn't true!

In the past, some degree of "grasping at straws" was certainly understandable. But with knowledge of highly effective practices and approaches now shared among researchers, interventionists, and parents, what is called for is rather a careful and critical review of the available options.

WHAT ARE THE BEST PRACTICES IN EARLY INTERVENTION FOR YOUNG CHILDREN WITH AUTISM?

Families and professionals want to know what they should do when a young child is diagnosed with autism. Parents may continue to look for possible causes to the disorder, and they may feel some guilt and hostility. But once a diagnosis is established, planning for early intervention should take place fairly quickly. The critical question then becomes, what do effective interventions look like and which one or which components of available practices will be right for a given child and family? For clinicians, the question will be how can they help a family go about selecting one format over another? To guide the answers to these questions this section will focus on two important reviews of comprehensive programs for early intervention in autism. Each review offers a critical analysis of program attributes and outcome data and then specific recommendations as to the common or shared elements of effective interventions. These reviews focused on comprehensive programs, that is, programs that offered a broad array of treatment services to the child and family. These were not treatments that targeted only one aspect of the child's autism. These programs tended to last for years and

they all, in their own ways, featured a high degree of intensity. By the very nature of the selection bias for comprehensive programs, the attributes of narrowly focused interventions are not addressed. These noncomprehensive programs may or may not have established their validity. Among the individual programs reviewed by the two studies featured here, questions continue to be raised about methodology and underlying philosophy. Many of these programs have important limitations and they have all continued to evolve and change. It may be fair to say that none of the comprehensive early intervention programs for children with autism meets the highest empirical research standards accepted within the fields of psychology or educational research (Gresham, Beebe-Frankenberger, & Mac Millan, 1999; Gresham & Mac Millan, 1998; Kasari, 2002). Yet, the information available on procedures, outcomes, philosophy, and goodness of fit within the current and emerging contexts for early intervention suggest that they each have earned at least a moderate degree of creditability. The first major review was commissioned by the Office for Special Education Programs, U.S. Department of Education, to examine educational interventions for young children with autism. The review was conducted by the National Research Council.

The National Research Council assembled an expert panel to come up with recommendations for early education and treatment for children with autism. This group, the Committee on Educational Interventions for Children with Autism, was made up of 12 distinguished autism researchers. Catherine Lord was the chair of the committee and James McGee served as study director. The product of the committee's work is published as *Educating Children with Autism* with Lord and McGee as editors (2001). One purpose of the study was to provide information to the U.S. Congress to enable legislators to make informed decisions on autism educational services for the Reauthorization of the Individuals with Disabilities Education Act Amendments of 1997 (IDEA). In an effort to widely disseminate these findings, the report, in its entirety, is on the Internet at http://www.nap.edu. The Committee established a set of criteria that first included the availability of published program descriptions and considered federally funded program efforts and model programs that had been presented at national workgroups for the National Early Childhood Technical Assistance System. From these sources, frequency counts were derived based on how many times a program was cited in the professional literature. Twelve programs were selected and invited to participate, with 10 programs accepting the invitation. Here is a list of the 10 programs and a very brief description of some keys features of the program models:

1. *Children's Unit at the State University of New York at Binghamton.* This program is for children with *severe behavior problems.* This program uses an applied behavioral analysis (ABA) model with careful goal selection and

a computerized monitoring system. (Romanczyk R. G., Lockshin, S. B., & Matey, L. 2001).

2. *Denver Model at the University of Colorado Health Sciences Center.* This developmentally oriented program relies heavily on *play activities to promote cognitive* growth with an emphasis on symbolic functions (Rogers, Hall, Osaki, Reaven, & Herbison, 2001).

3. *Developmental Intervention Model at The George Washington University School of Medicine.* This program uses a developmental model with a strong focus on *relationship development.* It also has a home component with intensive *floor-time* activity (Greenspan & Wieder, 1997).

4. *Douglass Developmental Center at Rutgers University.* This ABA program initially uses *discrete trial instruction* in segregated settings and shifts to more natural procedures and settings. It has an intensive home-based component (Harris, Handleman, Arnold, & Gordon, 2001).

5. *Individualized Support Program at the University of South Florida at Tampa.* This is a positive behavioral support, ABA-based program that, unlike the others noted here, serves as an adjunct to ongoing special education services. The program focuses on *in-home parent training* with relatively short but intensive services with ongoing follow-up (Dunlap, & Fox, 1999).

6. *Learning Experiences, an Alternative Program for Preschoolers and Their Parents (LEAP) Preschool at the University of Colorado School of Education.* LEAP relies heavily on bringing young children with autism into close and regular contact with typically developing children with extensive use of *peer-mediated social skills.* The program is a blend of behavioral and developmentally appropriate practices (Strain, 1987).

7. *Pivotal Response Model at the University of California at Santa Barbara.* This model relies on naturalistic application of ABA to *teach pivotal skills* for social and communication and self-management. It has clinic and home-based program with concurrent child participation in school-based special education (Koegel, Koegel, Harrower, & Carter, 1999).

8. *Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) at the University of North Carolina at Chapel Hill School of Medicine.* TEACCH uses an eclectic model with a reliance on a structured teaching approach and an emphasis on *visual supports.* TEACCH provides statewide services in North Carolina through regional centers (Mesibov, 1997: Schopler, Mesibov, & Baker, 1982).

9. *The University of California at Los Angeles (UCLA) Young Autism Project.* This program is an ABA program with reliance on *one-to-one discrete trial instruction* in home-based and parent-managed programs. The first emphasis is to teach the child basic learning skills, then language, and then skills for participation in less restrictive settings (Lovaas, 1987).

10. *Walden Early Childhood Programs at the Emory University School of Medicine.* The Walden Program operates from an ABA model with developmentally

influenced goal selection. It features an emphasis on *incidental teaching* with both center- and home-based components. Typically peers outnumber children with autism (McGee, Morrier, & Daly, 2001).

The panel made several recommendations, which, in light of its mission and funding sources, should have exerted a strong influence on national special education policy for young children with autism and related disabilities. At the time this chapter is being written, Congress as not concluded deliberations on the 2003 reauthorization. But it does appear that many of the recommendations made in the Committee report have not been incorporated into the bill. The recommendations remain as an excellent consensus statement and even as a rallying point for advocacy efforts. Page 6 of the executive summary, *Characteristics of Effective Interventions,* is shown as Figure 6.2.

Lord and McGee (2001) provide the following list of features of effective interventions noting that there was a high degree of consensus within their committee for these features:

Across primarily preschool programs, there is a very strong consensus that the following features are critical:

- Entry into intervention programs as soon as an autism spectrum diagnosis is seriously considered
- Active engagement in intensive instructional programming for a minimum of the equivalent of a full school day, 5 days (at least 25 hours) a week, with full year programming
- Repeated, planned teaching opportunities generally organized around relatively brief periods of time for the youngest children (e.g., 15 to 20-minute intervals), including sufficient amounts of adult attention in one-to-one and very small group instruction to meet individualized goals
- Inclusion of a family component, including parent training
- Low student/teacher ratios (no more than two young children with ASDs per adult in the classroom)
- Mechanisms for ongoing program evaluation and assessment of individual children's progress, with results translated into adjustments in programming (p. 219)

They then list six intervention priorities:

1. Functional spontaneous communication
2. Day-long social programming
3. Teaching of play skills
4. Other instruction for cognitive development carried out in natural environments

5. Proactive approaches to behavior problems
6. Functional academic skills when appropriate to the skills and needs of the child (p. 221)

The work of the Committee on Educational Interventions for Children with Autism brings importance to he work of intervention researchers and

CHARACTERISTICS OF EFFECTIVE INTERVENTIONS

What are the characteristics of effective interventions in educational programs for young children with autistic spectrum disorders?

There is general agreement across comprehensive intervention programs about a number of features of effective programs. However, practical and, sometimes, ethical considerations have made well-controlled studies with random assignment (e.g., studies of treatments that systematically vary only one dimension) almost impossible to conduct. In several cases, features have been identified through correlational or comparative analyses and then assumed to be factors of importance in intervention programs, without further direct evaluation.

The consensus across programs is generally strong concerning the need for: early entry into an intervention program; active engagement in intensive instructional programming for the equivalent of a full school day, including services that may be offered in different sites, for a minimum of 5 days a week with full-year programming; use of planned teaching opportunities, organized around relatively brief periods of time for the youngest children (e.g., 15- to 20-minute intervals); and sufficient amounts of adult attention in one-to-one or very small group instruction to meet individualized goals. Overall, effective programs are more similar than different in terms of levels of organization, staffing, ongoing monitoring, and the use of certain techniques, such as discrete trials, incidental learning, and structured teaching periods. However, there are real differences in philosophy and practice that provide a range of alternatives for parents and school systems.

The committee recommends that educational services begin as soon as a child is suspected of having an autistic spectrum disorder. Those services should include a minimum of 25 hours a week, 12 months a year, in which the child is engaged in systematically planned, and developmentally appropriate educational activity toward identified objectives. What constitutes these hours, however, will vary according to a child's chronological age, developmental level, specific strengths and weaknesses, and family needs. Each child must receive sufficient individualized attention on a daily basis so that adequate implementation of objectives can be carried out effectively. The priorities of focus include functional spontaneous communication, social instruction delivered throughout the day in various settings, cognitive development and play skills, and proactive approaches to behavior problems. To the extent that it leads to the acquisition of children's educational goals, young children with an autistic spectrum disorder should receive specialized instruction in a setting in which ongoing interactions occur with typically developing children.

FIG. 6.2. Characteristics of Effective Interventions.

the entire autism intervention community. This work benefits from the work of other summaries on the effectiveness of early intervention for children with autism.

Dawson and Osterling (1997) reviewed eight preschool programs for children with autism. They selected programs for which they found published data on intake and outcomes, as well as descriptions with statements of their philosophy and approaches. Their list included six programs (Douglass Developmental Disabilities Center, Health Sciences Center, Learning Experiences... An Alternative Program for Preschoolers and Parents [LEAP], Treatment and Education of Autistic and Communication-Handicapped Children [TEACCH], Walden Program, and the Young Autism Program) featured several years later in Lord and McGee (2001). They analyzed program data to determine, for example, that average entry age was 3.5 to 4 years with the Lovaas (1987) program having the lowest entry age at 2 years and 8 months. In considering outcome measures, Dawson and Osterling discussed the difficulty in using program placement as a measure of program effectiveness due to the administrative decisions that sometimes drove placement in some locales and the challenge of comparing results across the wide diversity of measurement approaches. They used the term "tried and true" (p. 314) to describe common elements and wrote, "Despite having different philosophical backgrounds and approaches, seasoned clinicians and researches dealing with children with autism are shaped by the common experience of working with these children. Out of this common experience have come basic shared beliefs and methods..." (p. 308). This view strengthened their analysis and assessment and resulted in a delineation of six common elements (plus a seventh factor is included dealing with intensity and other items).

COMMON ELEMENTS OF THE EARLY INTERVENTION PROGRAMS REVIEWED BY DAWSON AND OSTERLING (1997)

Element One: Curriculum content

1. Ability to attend to elements of the environment
2. Ability to imitate others
3. Ability to comprehend and use language
4. Ability to play appropriately with toys
5. Ability to socially interact with others

Element Two: Need for highly supportive teaching environments and generalization strategies

Element Three: Need for predictability and routine

Element Four: A functional approach to problem behavior
Element Five: Transition for the preschool curriculum
Element Six: Family involvement

Intensity of intervention and other common elements:

> And all programs feature a high degree of intensity of intervention (27 hours per week was the average) and share other common elements including (but not limited to) occupational therapy, augmentative communication methods, and the development of trusting, positive social relationship. (pp. 314–321)

Dawson and Osterling (1997) point out that children with autism tend to be able to learn tasks in high-support contexts but typically fail to be able to use newly learned skills in natural environments unless supplied with extensive support. They consider this one of the hallmarks of the child with autism and stress that context must be carefully considered when examining any child's performance. In discussing Element Two they write:

> In most programs, core skills are established in highly supportive teaching environments and then are systematically generalized to more complex, natural environments. Core skills refer to those skill domains that are inherently part of the autism syndrome and are critical for the acquisition of knowledge also referred to as "pivotal skills" by Koegel and Koegel (1988, p. 316).

A GROWING CONSENSUS ON EARLY INTERVENTION FOR CHILDREN WITH AUTISM

The combined works of Lord and McGee (2001) and Dawson and Osterling (1997) help to illustrate the growing consensus in the field of autism about what constitutes effective early intervention. Figure 6.3 shows the critical components found in each of these works. Although differing in some regards, primarily in the degree of emphasis, these two works display strong commonalities. There are at least eight very important common themes. These are:

1. Intervention should begin early.
2. Intensity of intervention-effective intervention is intensive intervention.
3. There are core skills or deficit areas to be addressed for children with autism.
4. There are an array of core techniques or approaches for responding to these core deficits.

5. Carefully planned teaching featuring an emphasis on predication and routine is essential.
6. Transition to next environments must be carefully addressed in skill selection.
7. The family of the child with autism must be a partner in the intervention.
8. There is general agreement as to the nature of effective early intervention for children with autism.

Dawson and Osterling, 1997

Element One: Curriculum Content

1). Ability to Attend to Elements of the Environment

2). Ability to Imitate Others

3). Ability to Comprehend and Use Language

4). Ability to Play Appropriately with Toys

5). Ability to Socially Interact with Others

Element Two: Need for Highly Supportive Teaching Environments and Generalization Strategies

Element Three: Need for Predictability and Routine

Element Four: A Functional Approach to Problem Behavior

Element Five: Transition for the Preschool Curriculum

Element Six: Family Involvement

Intensity of Intervention and other Critical Elements: [not named as an element but sharing an equivalent heading]

Lord and McGee, 2001

1. Intervention Begins Early
2. Intervention is Intensive in Hours
3. Families are Actively Involved in their Children's Intervention
4. Staff are Highly Trained and Specialized in Autism
5. Ongoing Objective Assessment of a Child's Program
6. Curriculum Provides Systematic, Planful Teaching
7. Focus on Communication Goals and Other Developmental Areas
   1). Communication
   2). Engagement
   3). Social interactions
   4). Play
   5). Cognitive and academic skills
   6). Self-help
   7). Behavioral challenges
   8). Motor skills
8. Carefully planned, Research-Based, Teaching Procedures Include Plans for Generalization and Maintenance of Skills
9. Individualized Intervention Plans are Needed to Adjust for the Wide Range of Children's Strengths and Needs
10. Transitions from Preschool to School are Planned and Supported

FIG. 6.3. Critical components found in two major studies of early intervention for children with autism.

Beginning Intervention Early

Among the clearest messages to emerge from recent work on early intervention in autism is the necessity of beginning intervention early. Supported by improved screening procedures and greater public understanding of autism, an understanding that extends to most parents and makes them aware of autism at some level, children are being identified much earlier. Early identification is important to provide access to early treatment options. The window of opportunity, or perhaps zone of opportunity from a neurobiological standpoint, can promote a positive enthusiasm and dedication to treatment or, if misunderstood, a careless rush to begin too soon.

In order to begin early, children must be identified early. Not surprisingly, screening for autism has received considerable attention in recent years (Baird et al., 2000; Fillipek et al., 2000; Robins, Fein, Barton, & Green, 2001; Stone, Coonrod, & Ousley, 2000). The essence of the challenge to develop good screening tools and then to make them widely available is captured here:

> "Autism is a common disorder of childhood. Yet, it often remains unrecognized and undiagnosed until or after late preschool age because appropriate tools for routine developmental screening and screening specifically for autism have not been available. Early identification of children with autism and intensive, early intervention during the toddler and preschool years improves outcome for most young children with autism." (Abstract of practice parameter: Screening and diagnosis of autism. *Neurology* (Fillipek et al., 2000), *55*, 468–479)

And even now the best screening instruments are not satisfactory, in their current form, to serve as the basis for the national screening agenda needed. The Child Neurology Society and the American Academy of Neurology have developed "Practice Parameters for the Diagnosis and Evaluation of Autism" (p. 439). They urge the use of a "dual-level approach: (a) routine developmental surveillance, and (b) diagnosis and evaluation of autism" (p. 439). General developmental screenings (or Stage 1 screening) made a part of the routine well-baby visits allow clinicians to refer children for autism and Asperger syndrome-specific screenings (often referred to as Stage 2 screening). Among the major issues, however, are the inability of most of the available instruments to work with children younger than 18 months for autism and less than 48 months for Asperger syndrome. Additionally, sensitivity of the instruments, especially with younger children, remains an issue. Efforts to improve screenings and make them more accessible to health care providers are underway. One promising effort is by First Signs, Inc., a nonprofit organization, "dedicated to educating parents and physicians about

the early warning signs of autism and other developmental disorders" (First Signs, 2003). First Signs provides excellent summaries of the issues of early-autism screenings, provides a comprehensive list and access information on the screenings, and has prepared a *First Signs Screening Kit* for physicians. In addition, this organization assists groups within states to strengthen early screening efforts.

Intensity of Intervention

For intervention to be effective it must be intensive. This was known with the first generation of early intervention studies and has been supported by a host of studies and the experience of comprehensive intervention programs. But to say that intervention must be intensive without objectifying intensity is futile. Dawson and Osterling (1997) determined an average number of hours for programs and came up with 27 per week. They noted that with the required or suggested parent time devoted to intervention that most of the programs they reviewed would be achieving about 40 hours each week. Lord and McGee (2001) arrived at 25 hours per week but further specified that this should be a minimum of 5 days per week and year round. Lovaas (1987) reports impressive results from a 40-hour program of home-based intervention.

Staffing is usually addressed in relation to teaching, but it comes into play in relation to intensity as well. Intensity also means having sufficient staff to provide many one-on-one opportunities for children who need them, usually during the early portions of their program. Then there should be sufficient personnel to have many very small group activities. Lord and McGee (2001) suggest that very small group sizes of two or three children should be used. With the characteristic problems of children with autism including social imperceptions, communication deficits, and the likelihood of behavioral challenges, it is obvious that these children will need lots of close support. But other children with disabilities can face somewhat similar combinations of problems. What is critical is that with an intensive program the children with autism make such dramatic progress. Without it they do not.

Due to the need for the highest levels of intensity, the general early intervention goal of partnership with parents takes on a different nature in autism. For programs to be most effective, parents must be not only highly involved but also *central* to the intervention effort. Parents must be active, in a direct and sustained manner in the intervention process. This permits extension of therapeutic benefit throughout the waking life of the child. This is not the tendency in most intervention programs.

Larsson (2003), with special reference to home-based behavioral programs, writes, "Both staff and parents typically expect the staff to fill the "expert" role and place responsibility on the staff to maintain quality control

over programming; however, these expectations subvert the therapeutic need to fully involve the parents in intervention. . . . supervisors should look beyond the staff hours to the family's 24-hour day to analyze where the treatment needs augmentation" (p. 313).

Larsson goes on to stress the importance of parents becoming skilled in training new staff members for home programs and taking over the central role in clinic meetings and decision making. This need for maximum parent involvement tends to favor the simplest and most robust forms of intervention. Here, parents can quickly learn how to participate and then lead the intervention effort.

What is exciting about the approaches that appear to have the best outcomes is that parents have come full circle from the earliest days of intervention when parents would be urged to send their child off to an institution to be cared for by "experts." Now parents manage the intervention. No matter how dedicated an interventionist may be, parents will be more dedicated and more determined to have strong outcomes for their child. This phenomena applies in the vast majority of cases. But what about the instances of weak or inconsistent parent involvement? Do those children then get a degraded intervention? This is certainly one of the criticisms of some forms of early intervention for autism. The answer would appear to be yes; in the absence of dedicated parent involvement, intervention outcomes will not be as good. The necessity for high levels of intensity in autism intervention require parents to assume a role that is new and that may well be the forerunner of the role for parents of children with other disabilities seeking to have optimized intervention outcomes (Hart & Risley, 1995, 1999).

There Are Core Skills or Deficit Areas to Be Addressed for Children With Autism

Children with autism have some unique features. These features challenge parents and professionals and these unique features are primarily problematic in relation to traditional teaching. But these characteristics give rise to special ways of teaching. Dawson and Osterling's (1997) use of the term "core skills" (p. 316) features these deficit areas in a positive mode and focuses attention on what can and should be done to help children learn. They specifically list five areas: attention to elements of the environment, imitating others, comprehension and use of language, ability to play appropriately with toys, and ability to socially interact with others (p. 316). They additionally point to the need for predictability and routine and the high risk for the development of problem behaviors. Lord and McGee (2001) list them as communication, engagement, social interactions, play, cognitive and academic skills, self-help, behavioral challenges, and motor skills. Each one of these areas can be the focus of a chapter or book, and the

purpose here is not to summarize the research on each skill area; rather, it is to highlight some common features for early intervention programs.

In order for children to learn, they must be able to attend to and interact with the adults and then other children in the teaching and learning setting. Children with autism are often initially resistant when asked to attend or interact especially with unfamiliar persons. But, with one of several techniques or combinations of techniques they can be helped to engage and attend. Most good efforts meet the child more than halfway with enticing objects and activities and high degrees of both antecedent and consequent cheerfulness. Unless a child is attending to another person they have no way to imitate the other person.

There Is an Array of Techniques or Approaches for Responding to Core Deficits

The Committee notes that certain techniques are common to effective programs "such as discrete trials, incidental learning, and structured learning periods" (p. 6). These techniques will be considered along with other common approaches of early intervention with young children with autism.

Discrete trial (DT) has come to be so closely associated with early intervention in autism that, for many, early intervention for these children is automatically considered DT (Fenske, Krantz, & McClannahan, 2001). This is obviously erroneous as Fenske et al. note, but it points to the widespread use of DT. Early intervention programs will commonly use a variety of techniques but discrete trial training (DTT) is the technique most widely used, especially in the early phases of the program. Smith (2001) provides a summary of DTT. He notes that each discrete trial has five parts:

1. Cue or technically the discriminative stimulus.
2. Prompt in which the teacher assists the child in responding to the discriminative stimulus.
3. Response in which the child either responds correctly, or incorrectly, or not at all.
4. Consequence followed by some immediate reinforcement. Incorrect responses get a signal from the teacher that indicates the response was incorrect.
5. Intertrial interval in which the teacher pauses between the just completed trial and the upcoming trial. This is usually just a few seconds. (p. 88)

These trials are used with a sequence of skills, trial-by-trial performance data are recorded with close monitoring by a program supervisor. DTT is very efficient for bringing about altogether new forms of behavior, for new discriminations and for teaching imitation, receptive language, expressive language, conversation, and grammar and syntax of sentences (Smith,

2001). Lovaas (2003) gives four benefits of DT: (a) DT clarifies exactly what the teacher is seeking to teach; (b) DT allows both teacher and student to know immediately if the response was correct or not correct; (c) DT promotes instructional consistency, which is especially important in the beginning stages of instruction of instruction; and (d) DT permits rapid and efficient determination of progress. Lovaas goes on to note that DT procedures are not limited to simple rote learning but are commonly used for teaching many higher level skills.

Few people who use DTT rely on it entirely even in the early phases of intervention. Smith (2001) notes that other behavioral teaching approaches are needed:

> "Both incidental teaching and other instruction approaches, such as peer model, videotapes, picture schedules, involve a more flexible format than DTT. Thus, these approaches may (a) be more effective than DTT for helping children transfer skills to new settings and (b) impose fewer requirement on teachers to present cues to children." (p. 90)

Discrete trial training should be viewed as an essential instructional skill for any teacher providing early intervention services to children with autism.

Pivotal Response Training

Koegel, Koegel, Frea, and Smith (1995) describe pivotal behaviors as those behaviors "that are likely to affect wide areas of functioning" (p. 7). Generalization is facilitated as the pivotal skills will be used in multiple settings on a very frequent basis. Motivation and responding to multiple cues are critical pivotal responses. Motivation is increased as overall response demands are made with consideration of the learning style of the individual child. This then reduces a host of problems typically associated with failure and task refusal. Close attention to motivational factors has become a cornerstone of the positive behavioral support practice. Children motivated to perform are also more likely to survey their environment and explore and learn in more typical ways. These approaches are packaged for use by teachers of children with autism as pivotal response training (Koegel, Koegel, & Schreibman, 1991) and should be considered essential training components for teaching personnel.

Incidental Teaching

Incidental teaching should play an important role in an instructional program for children with autism. Hart and Risley first described incidental teaching in 1968. They found that children who were hesitant to engage in traditional group language tasks could be motivated to use more elaborate

language when use of language was necessary for access to snacks and other activities the child wanted. In incidental teaching, the reinforcer is natural to the setting and not contrived. In order to use incidental teaching with children with autism, the environment is engineered so as to require children to communicate with adults to get what they need or want and the adults are poised to ask for increasingly higher levels of language. Fenske et al. (2001) explain how incidental teaching is done with children with autism:

> Wait for an initiation.
> Request elaborated language.
> Provide the object for which the child requested.
> Collect data. (pp. 77–78)

Application of incidental teaching strategies requires careful planning and arranging of materials and staff sensitivity to the sometimes unclear initiations of young children with autism.

The Walden School seeks to maximize the use of incidental teaching to promote social communication in their inclusive settings. McGee, Morrier, and Daly (2001) report that incidental teaching works well for both the children with autism and typically developing children and does require "teachers to maintain high levels of enthusiasm as they make a rapid series of complex teaching judgments... incidental teachers must constantly track children's interests to identify the perfect timing of the '"teachable moment"' (p. 168). In order for incidental teaching to work, teachers must pay very close attention to the often subtle expression of child interest and then be prepared to quickly deliver the target items and to verbally interact to further the communication experience.

Applied Behavior Analysis and Positive Behavioral Support

Early intervention for young children with autism is founded on a behavioral model. Schreibman (2000) writes:

> It is now widely acknowledged that, to date, the format of treatment enjoying the broadest empirical validation for effectiveness with individuals with autism are those treatments based upon a behavioral model... The science wherein these principles are applied to the improvement of socially important behaviors is known as applied behavior analysis, and the development of the behavioral treatment of autism is largely the result of this field of science. (p. 373)

The majority of the studies and programs featured in this chapter are built on a behavioral approach. Behavioral intervention has changed dramatically

although many may continue to see it as relying on the use of punishment or simple contingency management programs. The evolution has aligned with the complexity of behavior in the real world and the need to bring effective treatments directly to persons in need of them. As a powerful technology, there is concern for improper applications of behavioral technology. The behavioral analytic community has moved forward to determine the essential skills for a competent behavioral analyst (Shook, Hartsfield, & Hemingway, 1995). A certification process has been developed and is managed by a nonprofit credentialing agency (Moore & Shook, 2001). The demand for behavior analytic early intervention service providers was one of several factors supporting these initiatives.

The most important change in behavior analysis in relation to early autism intervention is the growth of positive behavior supports (PBS). At least six critical elements help to define PBS: comprehensive lifestyle change, a life-span perspective, ecological validity, emphasis on prevention, flexibility in scientific practices, and multiple theoretical perspectives. PBS seeks to strengthen personal competence and environmental integrity. Carr et al. (1999) synthesized the research on PBS and determined it has been effective in helping bring about long-term durable changes, with positive and proactive methods for persons across a wide range of disabilities.

Functional assessment procedures are highlighted as a process for understanding the function or functions of problem behaviors and then using this information to form hypotheses that serve to unify support and intervention efforts. Interventions based on a functional assessment have been shown to be more effective than interventions that are not based on this type of information (Carr et al.).

Horner et al. (2002) examined interventions for problem behavior for young children with autism. The synthesis was limited to children 8 years of age or younger and looked at issues such as the nature of problems reported, the nature of interventions used, the effectiveness of interventions, and specificity of interventions all with a focus on the contribution of PBS. This article listed eight major findings:

1. Stereotypy, self-injury, and aggression are the problem behaviors most often studied.
2. A wide range of intervention practices has been studied.
3. Behavioral intentions are effective.
4. The diagnosis of autism is not related to the type of intervention employed or likelihood of intervention success.
5. Functional assessment increased the likelihood of intervention success.
6. Typical agents [natural support persons] are associated with improved effects.

7. Systems change procedures increase the likelihood that intervention will be effective.
8. Insufficient data are available to document factors affecting generalization and maintenance. (pp. 428–429)

Among the findings of this review is the fact that disruptions and or tantrums were the problem behavior most likely to be addressed. In relation to effectiveness, the findings are particularly encouraging. The authors suggest that: "There is reason for significant optimism that early use of behavioral intervention can result in reduction of problem behaviors by 80 to 90%." (p. 434). With such reductions coupled with extensive skill development efforts, the profile of young children with autism is undergoing a change toward higher levels of competence and far lower levels of problematic behaviors.

Communication

Great strides have been made in enhancing the communication skills of young children with autism, yet this remains an area in need of focused research (Koegel, 2000). Goldstein (2002) provides a comprehensive review of interventions, noting the broadening scope of research. Whereas discrete trial training continues to be a major feature in comprehensive programs, packages of multiple teaching strategies are becoming more prominent for targeted communication development. Such approaches tend to focus on the natural reinforcing contingencies for communicating, understanding, and then exploiting the motivational variables that would naturally support language and interventions that can be used across settings (Hwang & Hughes, 2000; Klinger & Dawson, 1992; McGee et al., 1999). These interventions are immersed in a social context and the child is usually taught how to recognize the opportunities to communicate with peers, how to initiate communication, and how to terminate the interaction.

Although social communication programs are becoming more prominent, interest continues to grow in alternatives to discrete trial intervention for language. A persistent concern about discrete trial intervention of language is that the telegraphic form of the instructions (discriminative stimulus) and the high levels of structure conspire to make the child overly dependent on these features and inhibit spontaneous language. Delprato (2001) conducted a comparison of DT and normalized language intervention techniques. He characterizes the normalized interventions by writing that they "consist of loosely structured sessions of indirect teaching with everyday situations, child initiation, natural reinforcers, and liberal criteria for presentation of reinforcers" (p. 315).

Sundberg and Partington (1998) have refined a set of teaching strategies that again focus on the natural motivational variable to promote language. These verbal behavior strategies are based on Skinner's (1957) analysis of verbal behavior. Skinners's work focused not on traditional receptive and expressive understandings of language but rather on the functions served by various forms of verbal behavior. For example, *mands* or expressions of need are motivated by the child needing or wanting something. *Tacting* serves to label an object or action (Sundberg & Partington, 1998). Early phases of verbal behavior training tend to emphasize manding, with target materials consisting of items in the child's natural environment and ones with which the child is highly motivated to play. For example, bath toys can be placed on a bathroom storage shelf, enticing the child to ask for them one at a time. Partington (2003) remarks that in this way "the world is one big training opportunity."

These studies and program features are representative of the newer emphasis on more natural approaches to early language development and the quest for higher natural levels of motivation found in early communication development with young children with autism.

Social Skills With an Emphasis on Generalization

Brady, Shores, McEvoy, Ellis, and Fox (1987) illustrate how a focus on core deficits can yield intervention procedures that should become core teaching skills for interventionists. The Brady et al. study culminated in a series of studies in which the researchers validated the Stokes and Baer (1977) suggestion that training across multiple training examples could promote a generalizable behavior change. In previous research, a number of authors showed that many children with autism would learn to interact with other children, but only when directly taught to do so, and only with the peers who had been involved in the training. In the generalization studies, Brady et al. demonstrated that directly teaching children with autism to initiate or to respond to more than one other child increased the likelihood that the children would then extend this new social behavior to other peers who were not part of the teaching procedure. Across a series of studies, the researchers found that most children with autism demonstrated generalizable social behavior after participating in the training procedures with either *two or three* "training confederates." Once the children with autism learned a set of social behaviors (initiations, responding to others' initiations) and had the opportunity to practice this behavior set with a small number of other children, the children with autism spontaneously applied their new social skills to other peers who were not "trainers."

Although this kind of intensive programming is obviously time consuming, it can result in broadly applicable or highly generalizable gains. As such,

it must be seen as among a core of skills that should be taught to young children with autism.

Taylor and Jasper (2001) provide detailed programs for promoting peer socialization, such as "Look at peer when instructed by adult, and establish eye contact when name is called by peer" (pp. 100–101). These programs feature instructions for the child with autism and the typical peer, strategies for generalization, and importantly, procedures for making the role of adults less prominent over time. These types of highly structured programs will typically be necessary in the early phases of social instruction. Children placed in inclusive settings who lack such skills will experience a great deal of difficulty, and even if provided with a shadowing aide, real social interaction with peers may be negligible.

Carefully Planned Teaching Featuring an Emphasis Routine is Essential

The very wide range of skills of these children simply requires a high degree of individualization. Not all teachers are trained to plan and teach in this way. Special education teachers are prepared to provide individualized instruction. In addition to knowing about individualization of instruction, teachers should understand autism. They should have knowledge of the sequence of skills to be taught, and of how to obtain and use assessment information. They must then process all of this information to plan and then deliver instruction. Presentation of skills must be done in such in ways that maximize the chances of correct responding while minimizing the chances for error. It is not uncommon to see older preschool children doing worksheets that have been generated merely to keep them busy. This is exactly the opposite of what should be happening in classrooms. Careful teaching and attention to materials are critical.

High Degrees of Structure

High degrees of structure help with predictability and interact with the child's need for routine. Structured teaching characterizes the TEACCH curricular approach. The TEACCH structured teaching model has four main elements including schedules, work systems, task organization, and physical structure and organization (Schopler Mesibov, & Hearsey, 1995). Language and socialization activities are taught throughout the day but emphasized in designated and structured areas of the classroom. One of the refinements of the TEACCH model for preschool age children is providing children with many shorter tasks and activities when contrasted to the programs for older children. Daily individual schedules typically feature pictures and text and

allow the child, from the earliest possible ages, to visually appraise upcoming and completed tasks. Schedules are adjusted to the child's level and in this way minimize problems with behavior. Mesibov, Browder, and Kirkland (2002) suggest that the TEACCH reliance on individualized schedules as a "predicator strategy" yields important benefits in promoting autonomy and generalization of skills, resulting in a reduction of problem behavior. TEACCH has been a pioneering program in the use of visual strategies to increase predictability, making the environment more comprehensible to persons with autism. Arranging the environment in such a way as to highlight when any given task or activity is completed and strengthening the "concept of finished" become key motivators for many persons with autism (Cox, 2002). This also functions as a way of teaching waiting, an important skill and one that is essential for the prevention of many problem behaviors.

Another way of combining careful teaching with prediction and with respect of the need for routine most children with autism have is found in script fading and the use of photographic activity schedules. Script fading and photographic activity schedules (Krantz, MacDuff, & McClannahan, 1993; Krantz & McClannahan, 1993) have been used to teach social interaction skills, promote participation in family activities, and teach independent access to a variety of leisure skills. The scripted material is systematically faded, permitting the child to have the support of the supplemental materials while allowing for systematic reduction to the lowest degree appropriate for that child. Photographic activity schedules allow the teacher or parent to develop a sequence of photographs for use in prompting the child through a series of activities. Both of these procedures seek to minimize the adults' role and the possibility that children will become dependent on prompts.

Transition to Next Environments Must Be Carefully Addressed in Skill Selection

Young children with autism do not stay young long. The child who is identified at 36 months of age may be ready, chronologically, for kindergarten in just 2-years. Individual needs, however, must be the first consideration and most children with autism will develop according to their own timetable. No matter how they progress, children must be educated in the least restrictive setting. When children are given access to especially intensive early settings, this means that a change of level in intensity will be necessary. This can be a challenge for some families who may wish to maintain the highest possible levels of intensity. (This typically calls for the highest levels of restrictiveness as well.) But as the child becomes older, maintaining the intensity of a good early intervention program is not wise. Children must move on. For this to

happen, the child's program must be carefully planned to ensure the child is ready for the specific demands of the next environment.

Certain basic skills are needed for any child to get along or survive in school. These survival skills for young children with autism have been recommended by Powers (1992):

Compliance to adult request
Turn-taking
Listening to directions from afar or near
Sitting quietly during activities
Volunteering
Raising one's hand to solicit attention
Walking in a line
Using toilets in classroom versus in the hallway
Picking up toys after use
Communication of basic needs/wants (p. 244)

Johnson, Meyer, and Taylor (1996) provide an expanded list of skills they identify as prerequisite for inclusive settings. They delineate skills in the areas of language, social, academic, and behavior. Their social skills lists consists of:

a. Takes turns during activities
b. Waits quietly
c. Reciprocates greetings
d. Participates in circle games
e. Initiates play activities with peers with or without adult prompts
f. Initiates peer play (p. 333)

These skills and any similar skills that can be spotted as critical in the next environment should be targeted for instruction.

Another aspect of transition that can be a challenge for professionals and families is selecting a classroom. There may not be many choices from which to pick. Parents and others assisting with the child's program will want to consider all options and visit the ones that hold the strongest prospects for success. The proximity of the school to the child's home is an obvious first concern. Johnson et al. (1996) provide five factors to consider: chronological age of the other children in the proposed class, proximity of the proposed class to the child's home or specialized school, teachers who are structured and willing to be supported by a classroom aide, class schedule with an emphasis on the primary objectives for the child (social focus should feature a strong set of social activities or if an academic focus, a strong academic focus), and finally, classes with smaller numbers of children. Selection of the school may be less important than selection of the teacher.

Teachers who are structured yet flexible, able to smoothly manage a classroom with a positive climate, open to suggestions, and willing to try new ideas tend to be most effective.

The Family of the Child With Autism Must Be Involved in the Intervention

In no other area of disability does this seem to be so important as in autism. The need for intensity requires that parents be true partners. But the direction of this partnership is not always one in which professionals invite parents to partner with them. In many cases, the parents invite the professionals to join them. The parents will select the level of partnership with which they are comfortable. In preschool programs, this should, at minimum, entail attending the IEP meeting and other essential planning meetings. Beyond this is the option to participate in school–home notebooks that can be carried back and forth each day with parent entries read by the teacher and teacher entries read by the parents. Parents should be encouraged and supported to learn all they can about autism, skills development, positive behavioral support, and their educational rights and responsibilities. Whether they wish to do this is up to them.

PART C AND EARLY INTERVENTION IN AUTISM

With the passage of Public Law 99-457, the Education of the Handicapped Act Amendments of 1986, came a new era in early intervention services for preschool children. And as intervention for children with autism increasingly begins at younger ages, this law holds special promise for these children and their families. This section of IDEA was originally called Part H and redesignated Part C with the IDEA Amendments of 1997. With this act, the U.S. Department of Education assists the states in forming and maintaining statewide, comprehensive, coordinated, multidisciplinary, and interagency systems. The congressional intent was to:

- Enhance the development of infants and toddlers with disabilities;
- Reduce educational costs by minimizing the need for special education through early intervention;
- Minimize the likelihood of institutionalization, and maximize independent living; and,
- Enhance the capacity of families to meet their child's needs. (Danaher, J. [2001] National Early Childhood Technical Assistance Center [NECTAS] Web site. Retrieved May 17, 2003. http://www.nectas.org/~pdfs/pubs/nnotes9.pdf

Part C assists the states in providing services for children with disabilities from birth to 3 years of age and their families. Each state must have a lead agency to administer the program. In most states this is not the department of education. State programs must meet, at minimum, specific components by developing policies for comprehensive multidisciplinary evaluations, child find, a public awareness program, procedural safeguards, and a state interagency coordinating council among others. These components are featured in Figure 6.4.

Preschool children, older than 3 years of age, with disabilities are served under IDEA Part B. This embraces children ages 3 to 21 years. Unlike Part B services, Part C services tend to look very different across the United States reflecting varied histories, emphases, and priorities within each state. A statewide council and regional coordinating councils are to be in place to provide guidance to the state program and help identify and remove barriers to the delivery of coordinated services. As with other IDEA services, procedural safeguards are to be developed in alignment with Part C rules. The most fundamental and important difference between Part B and Part C is that, whereas Part B is child centered, Part C is clearly family centered. After a comprehensive, multi-disciplinary evaluation of the child and of family needs, an individual family support plan (IFSP) is developed. This is done with family members as fully empowered and equal members of the team. Selection of services is guided by the team. The actual amount of service or reimbursement rates may be set by state guidelines, but is not addressed in the federal regulations.

Family-Centered Programming

Part C is a family-centered program. Dunst, Trivette, and Deal (1994) have been influential in shaping the understanding of the concept of *family centered* as embraced by Part C. Dunst and his colleagues enumerate eight features of this approach:

1. Adoption of a social systems perspective of families that suggests a new and expanded definition of intervention.
2. Movement beyond the child as the sole focus of intervention, toward the family as the unit of intervention.
3. Major emphasis upon empowerment of families as the goal of intervention practices.
4. A proactive stance toward families that places major emphasis upon promotion of growth producing behavior rather than treatment of problems or prevention of negative outcomes.
5. Focus on family, and not professionally identified needs and aspirations as the primary target of intervention.

Minimum Components Under IDEA for a Statewide, Comprehensive System of Early Intervention Services to Infants and Toddlers With Special Needs (Including American Indian Infants and Toddlers)

1. Definition of developmental delay
2. Timetable for ensuring appropriate services to all eligible children
3. Timely and comprehensive multidisciplinary evaluation of needs of children and family-directed identification of the needs of each family
4. Individualized family service plan and service coordination
5. Comprehensive child find and referral system
6. Public awareness program
7. Central directory of services, resources, and research and demonstration projects
8. Comprehensive system of personnel development
9. Policies and procedures for personnel standards
10. Single line of authority in a lead agency designated or established by the governor for carrying out:
    a. general administration and supervision
    b. identification and coordination of all available resources
    c. assignment of financial responsibility to the appropriate agencies
    d. development of procedures to ensure that services are provided in a timely manner pending resolution of any disputes
    e. resolution of intra-and interagency disputes
    f. development of formal interagency agreements
11. Policy pertaining to contracting or otherwise arranging for services
12. Procedure for securing timely reimbursement of funds
13. Procedural safeguards
14. System for compiling data on the early intervention system
15. State interagency coordinating council
16. Policies and procedures to ensure that to the maximum extent appropriate, early intervention services are provided in natural environments
17. Procedural safeguards
18. System for compiling data on the early intervention system
19. State interagency coordinating council
20. Policies and procedures to ensure that to the maximum extent appropriate, early intervention services are provided in natural environments

Danaher, J. (Ed.). (2002). Part C updates. Chapel Hill: The University of North Carolina, FPG Child Development Institute, National Early Childhood Technical Assistance Center. Used with permission.

FIG. 6.4. Components of IDEA, Part C for State Early Intervention Programs.

6. Major emphasis on identifying and building upon family capabilities as a way of strengthening family functioning.
7. Major emphasis upon strengthening the family's personal social network and utilizing this network as a primary source of support and resources for meeting needs.
8. Shift and expansion in the role professionals play in interactions with families and the way in which these roles are performed (p. 4).

Many families of children with autism are already, or quickly becoming, empowered in the sense proposed by Dunst et al. (1994). Relying on these features of a family-centered model of services, parents of children with autism who wish to pursue intensive, systematic intervention should be afforded easy access by any family-centered service system.

Common Service Provision Arrangements in Part C

Under Part C, each state is to have a lead agency, and all lead agencies are required to assure that children receive a multidisciplinary evaluation that assesses all areas of development. The evaluation, which establishes eligibility and the initial IFSP, must be developed within 45 days of referral. The services a child receives are determined by a family support team that includes the family as an equal partner and uses the evaluation information as the basis for planning. The services for a child should be tailored to the needs of that child and his family. Because of the rapid development that takes place in the first 3 years of life, the IFSP must be reviewed at 6-month intervals, and a new IFSP must be developed annually.

Part C Service Guidelines for Early Intervention for Autism

Part C services are helping to bring early intervention to many thousands of children with autism. As part of a commitment to children with autism, some states have developed specialized service guidelines. The Georgia Part C/Babies Can't Wait program guidelines serve as an appendix to the state plan. These guidelines feature a review of characteristics of the pervasive developmental disorders and summary of the research on effective intervention. They go on to note that daily data collection, a balance between directive and responsive teaching, and the apparent advantages of behavioral approaches are all critical factors for interventions. Reimbursement rates are specified for interventionists with differentiated rates for approved approaches and a tiered-payment arrangement for supervisory and direct intervention personnel. The guidelines list five specific approaches that will be supported and funded by Babies Can't Wait when procedural requirements have been fairly met. These approaches are:

1. *Greenspan* (also known as floor time, developmental individual-difference, relationship-based [DIR])
2. *Applied behavior analysis:* (Also known as discrete-trial [DT], discrete-trial-training [DTT], intensive behavior intervention [IBI], behavior modification, structured teaching)
3. *Incidental teaching* (also known as milieu teaching, activity-based intervention [ABI], pivotal response, Walden approach)
4. *TEACCH* (treatment and education of autistic and related communication—handicapped children)
5. Denver model (based on the work of Sally Rogers; (pp. 16–18).

By providing clear guidance on those approaches and therapies that are supported and funded and noting those that are not, the Georgia Part C/ Babies Can't Wait Program provides clarity to families and professionals. This is likely to have the effect of reducing parent confusion and misdirection, allowing for a concentration of training efforts, and streamlining the IFSP process.

The Ontario IBI Initiative

The provincial government of Ontario, the most heavily populated province in Canada, has begun a major effort to provide intensive behavioral early interventions for children with autism. This is called the Ontario IBI (intensive behavioral intervention) Initiative. The impetus for this effort comes from two directions. First it derives from a court case brought by the family of a young child with autism from British Columbia. The family, joined by other families with children with autism, alleged that intensive intervention was a "medically necessary service" and the province's refusal to provide these services was discriminatory.

The British Columbia Supreme Court found in favor of the families and ordered funding of intensive behavioral intervention for children with autism, ages 0 to 6 years. The other provinces followed this ruling, with some variation in the nature of services provided. The province of Ontario alone allocated new funding of $20 million (Canadian dollars) to institute a system of IBI services for children 0 to 6 years of age. It is estimated that the commitment will reach a total of $100 million (Canadian dollars) by July 2007. To support this effort, training was funded for professionals featuring best practices in identification, diagnosis assessment, and specific techniques in early behavioral intervention for children with autism. Parent training is a key element of the initiate with the expectation that families will support their child's treatment at home. An evaluation component will determine the overall effectiveness of the program. Program services are being provided by regional service providers throughout this large province

with these programs obligated to provide services directly or by contract with other organizations. Families have the option, under the provisions of the regulations, to purchase behavioral intervention services privately. With this array of services in place, it is felt that this service gap or discrimination against children with autism will be closed and that children with autism and their families will be able to optimize their chances of success and have a far higher quality of life.

This brief treatment of the IBI Initiative would be incomplete without mentioning recent developments in relation to parent demand for intensive behavioral services. In January 2003, a group of over 50 families of children with autism over the age of 6, began taking action seeking IBI services.[2] Access to these services had been limited to children under the age of 6, and the families allege that this was, in light of the needs of their children, discriminatory. These claims are still pending but can be seen as a strong source of support for the availability of these types of intervention services.

Regional Agencies and Support Programs

An array of support organizations have been developed to provide families with direct support for home intervention. These organizations typically link parents concerned with quality early intervention with the public agencies that have a responsibility to provide intervention and other services to their children (Huff, 2003). Although Autism Society of America (ASA) chapters have been established in many communities for some years, the proliferation of direct support organizations is a more recent development. ASA has a policy of refraining from endorsing specific treatments or approaches preferring to share information on all available options with families, but many direct support organizations tend to endorse some methodologies and reject others. A parent organization, notes Huff, "... creates timesaving services by networking within the community, establishing work teams, and accumulating and distributing information" (p. 352).

Families for Early Autism Treatment

Families for Early Autism Treatment (FEAT) was established in 1993 by families in the Sacramento, California, area to promote and improve the quality of early intervention services for children with autism (Huff, 2003). Among their goals was to provide ABA programs to young children whose families wished to have them. FEAT has sponsored a number of conferences on autism, produced a video on early direction of autism, and directly assists families in obtaining quality intervention programs. FEAT has a parent

[2] Additional information on this issue is available at http://www.autismtoday.com/articles/Ontario_Human_Rights.htm.

mentor program which is able to help families with IEP issues, planning conferences, and due process hearings. The organization holds monthly meetings for parents and regular training sessions for professionals and parents on autism intervention. In addition, they maintain an extensive Website featuring a newsletter, resource documents, and a comprehensive listing of autism intervention professionals and agencies. FEAT serves as a network for information on autism intervention and has been active in state and national policy efforts. FEAT organizations have been established in over 23 regions of the United States and Canada. These organizations may provide direct intervention services, as well as training for parents and interventionists.

Reaching Potentials[3] (RP) was established in 1995 in south Florida by a group of parents of children with autism. These parents faced limited treatment opportunities and believed that behavioral intervention was not widely accepted. These families, sensing an overwhelming demand for intensive intervention services worked to increase public awareness and develop a network of training and support staff for home-based interventions programs. RP has sponsored several conferences, provided workshops for school districts and agencies, and partnered with an array of universities to provide training to university students. A key feature of RP is frequent training for home intervention staff. In this way, RP functions as training cooperative as costs for initial training are effectively shared across many families. Monthly beginning-level training is followed by higher level classes, which may focus on data collection, activity schedules, PECS overview, precision teaching, and other topics. RP also offers a program supervision model with monthly clinical consultation, twice-monthly in-home consultation and weekly discrete trial staffing. A workshop model is also available with an intensive 2 to 3-day workshop, which is supported by weekly data review by fax or e-mail, weekly telephone consultations, and monthly video reviews with follow-up workshops every 1 to 3 months.

Families for Early Autism Testament and RP are just two of the many new organizations that represent the trend in family-directed nonprofit organizations dedicated to helping families take advantage of intensive intervention approaches for their young children.

Parent-Directed Home-Based Early Intensive Behavioral Intervention

Families of children with autism are seeking early intensive behavioral intervention (EIBI) for their children in increasing numbers. There is not an accurate estimate at this time of the total number of families pursuing this

[3] Reaching Potentials, Inc. http://reachingpotentials.org. Phone: Florida, 561 274-3900; Virginia, 540 368-8087.

intervention option, but several electronic sites devoted to the topic have well over 1,000 subscribers. There may be as many as 10,000 families in the United States and Canada now engaged in what they describe as a home behavioral intervention program.

Although these programs differ widely in character, they commonly share some key features. Parents strive to begin early in the life of the child. Beginning at 2 years of age is now common. Intensity is a key element as families try to have from 20 to 40 hours of intervention each week. The Lovaas (1987) standard of 40 hours, although very difficult for families to manage, serves as a goal for many. The programs tend to be behavioral in nature. Families rely on an array of applied behavior analytic techniques and concepts (Baer, Wolf, & Risely, 1968), including the use of careful program designs and intervention sequences, performance data, and fast-paced and structured training activities with high levels of positive reinforcement. Green, Brennan, and Fein (2002) provide a complete description of a model program for a toddler.

What Happens in a Home EIBI Program?

In the most basic terms, this is what happens. First, parents, when receiving a diagnosis of autism for their child and after considering treatment options, decide to initiate the program. The parents obtain training or, in some cases, become self-taught. They hire a program supervisor and recruit trainers to assist with the program. If necessary, the parents arrange to have untrained people trained. Then they establish a schedule, assemble materials, and begin.

Jacobson (2000), in an article entitled "Early Intensive Behavioral Intervention: Emergence of a Consumer-Driven Service Model," notes that parent support for such programs has exerted considerable public policy influence and that parent advocacy is calling for "fundamentally better early intervention services that are available and accessible, provide active intervention, and are based on principles of behavior analysis" (p. 149). Jacobson and Mulick (2000) have argued that it will be, over time, cost effective for governmental sources to fund home programs and that such funding could help to raise the quality of current programs. They characterize the current situation as a "cottage industry" (p. 588) with many good features such as high level of parent control and involvement but one that is inherently difficult to fund under third-party arrangements. In such programs, they note, it is also very difficult to have reasonable degrees of treatment fidelity. Obtaining professionals with appropriate training and credentials is yet another issue (Scott, 1996; Shook & Favell, 1996). Marcus, Rubin, and Rubin (2000) challenge Jacobson and Mulick's assumptions and the research base for EIBI. These three works (Jacobson; Jacobson & Mulick; Marcus et al.) all point to the complexity of public funding as well as to the significance of

EIBI. Although funding and public policy are important, this enthusiasm, which has clearly taken on the character of a movement, was not simply the result of the research reported by Lovaas in 1987.

Let Me Hear Your Voice: A Family's Triumph Over Autism (1993)

Catherine Maurice detailed her early intervention experience in *Let Me Hear Your Voice: A Family's Triumph Over Autism* (1993). Maurice tells of her search for effective treatments for her daughter Anne-Marie, filled with conflicting, misleading advice from some prominent professionals in the New York City area. She details how she was urged *not* to consider behavioral intervention, as it would amount to treating her child like a robot. Maurice, cautiously at first, instituted an EIBI program and began to see rapid progress. Her family achieved considerable success with Anne-Marie and then with her son, Michel. Cohen and De Carlo (1995) reported on the recovery of the two children. Her story helped foster an international enthusiasm for EIBI that continues to this time. It also inspired controversy and bitter personal attacks that Maurice has labeled "trench warfare" (p. 1).

Perhaps the most contentious element of Maurice's work and the most misunderstood is the notion of recovery. She writes, "Nevertheless, there is hope—for improvement, for progress, and in some cases, for recovery. Even when there is no full recovery, autistic children can be helped—sometimes very significantly through different therapeutic approaches" (p. 271).

Lovaas (1987) had used the term "recovery" as a table heading for those children who had achieved best outcomes. But it was to be Maurice's use of the term, even conditionally, that provoked many in the professional and advocacy community. What she did with her writing was to share the hope that parents might fairly envision a treatment that could, for some children, allow for recovery from autism. Although this may have seemed incendiary in 1993, subsequent studies provide support for the general assertion. Certainly Dawson and Osterling (1997) suggest that with dedicated application of what was then [1997] known, that one-half of the young children could be successfully placed in general education classrooms. These researchers also reported that 50% of children in six programs studied made progress sufficient to be placed in regular education classes, and that for programs that reported IQ data, the average IQ gain was 20 points. They concluded that "approximately half of the children responded very positively to early intervention, and all or at least most children reportedly made significant gains" (p. 314). A parent statement about their experience with a home-based early intensive behavioral intervention appears as Figure 6.5. This intervention effort took place in New York State and the resources provided there are not reflective of those provided in most other parts of the county.

Jack, approaching two years old, was constantly sick. Jack's speech, which has been coming in nicely around 18 months, essentially disappeared. He rarely initiated interaction with people and displayed disturbing behaviors: staring at fans, spinning/ lining up objects, hiding in corners and staring blankly. Our pediatrician was useless in providing any insight. After months of agonizing we had Jack checked by developmental experts. By his second birthday, Jack was diagnosed with PDD-NOS. As part of our digesting the shock of this diagnosis, one expert indicated that Jack might never speak or live independently.

We went into action immediately. First, we met with parents of an autistic child in North Carolina who felt they had wasted a year on an ineffective program. They relocated a Lovaas instructor to start an applied behavior analysis (ABA) program. They strongly recommended ABA for Jack and insisted we read *Let Me Hear Your Voice.* As we lived in New York and relatively close to the Alpine Learning Group, they also recommended we talk to Bridget Taylor.

Within 3 months of Jack's initial diagnosis, we were fortunate to be accepted by Alpine's Outreach group (its home based program) and to secure funding for Jack to have 40 hours/week of ABA from New York State's Early Intervention program.

During the first six months of our ABA home program it was apparent to us that Jack's instruction would be ineffective and useless until Jack got his head "in the game" and began attending. As Jack was doing speech, OT and play dates, the time spent on these programs was a waste until Jack began attending and focusing. In addition, we as Jack's parents and his caretakers, worked 24/7 in stopping self-stimulating activities.

Within 12 months of getting ABA services, Jack, at 3.2 years, had developed sufficient basic learning and interactive skills to be able to attend a preschool for typically developing children with an aide. We felt it critical for Jack to model typically developing peers in addition to continuing his home-based ABA.

Jack currently "presents" as a funny, charming boy who's a little behind in speech and fine motor skills and has attention issues. Jack's eye contact is excellent when focused; he has developed relationships with his peers (including several girlfriends!) and has deep attachments to people. By his 4th birthday Jack knew the alphabet and his numbers and sight read some words.

This fall Jack will be working with an ABA center-based school in NJ, in developing his group attending and learning skills. He'll attend a preschool for typically developing children three days a week (versus five) so that we can jump-start his group learning abilities, using an ABA approach, while he's still a pre-schooler.

Statement from Optimistic Parents in New York City.

FIG. 6.5. A family statement on the benefits of intensive early intervention.

Of course, general education program placement is not the same as recovery, but with advances in early identification and treatment, what appeared in 1993 as extreme has by 2003 become the expectation for most comprehensive early intensive intervention programs. Maurice made it acceptable for parents to even hope for recovery for their child. In doing so she dramatically raised the family expectations in terms of quality, intensity, and commitment for a program of early intervention for their child or children with autism.

Instructional Techniques in Home Programs

DTT is the most common technique used in home programs. It is relatively simple to instruct inexperienced staff in the use of this technique, and it has a host of relative advantages. The nature of the technique and the purpose of DTT have already been presented. But it is important to consider some of the criticism of DTT, specifically in relation to home programs. Some critics fault EIBI for relying too heavily on DTT and certainly some poorly resourced home programs do rely too heavily on DTT. The relative simplicity and robustness of DTT appears to be one of the factors that have allowed it to be viewed as a practical approach by countless families.

Characteristics of Home Programs

The simplicity of EIBI has permitted parents to, manage their own home program. Scott (2003) reported results of a survey of parents conducting home EIBI programs. The average age of the child at the beginning of the program was 35.5 months, with 58% of all children beginning before 36 months of age and 29% beginning prior to 24 months of age. The total number of the children in the family was 2.8 and the average number of interventionists who had hands-on contact with the child on a weekly basis was reported at 4.3 persons. Over 90% of parents reported employing students, primarily university students, as teaching assistants. Pay averaged just under $20 per hour for the most senior teaching assistants and $11.74 per hour for the least senior assistants. When asked to rate the degree of difficulty in recruiting and maintaining teaching assistants, over 80% of parents rated this as somewhat or very difficult. Parents were asked to indicate the total number of hours of home-based direct behavioral intervention provided for the child each week. The average was just 21.5 hours. It is important to note that some children may have been receiving other interventions outside of the home. In any case, this is well below the 40-hour level used in the Lovaas (1987) research and the 25 to 27-hour per-week levels cited in recent summaries of effective inventions (Dawson & Osterling, 1997; Lord & McGee, 2001). However, this amount of time is very similar to the weekly training hour totals found in one study reporting progress in home-based EIBI

programs (Sheinkopf & Siegel, 1998). Several questions on the survey related to program supervision. The average number of hours of direct support on a monthly basis was reported as 7.7 hours (1.92 hours per week). The average hourly supervisor pay rate was over $77. No effort was made to determine the credential or qualifications of the program supervisor, but they are likely to have varied to a great degree. Not surprisingly, parents expressed a high degree of satisfaction with their home program with an average rating of 1.5 on a 1 to 5-point scale with 1 being very satisfied and 5 being very dissatisfied. Parents were asked to estimate the total annual program cost, excluding the value of the time spent by immediate family members. The average yearly cost estimate was $46,980. Asked if the family received any outside financial assistance with the program, the majority (52%) said no. Most programs are not only parent managed but also parent funded. Finally, parents indicated that, on average, they spent 974 hours per year or 18.7 hours each week managing, overseeing, and directly participating in their child's program.

Aversives in Lovaas Programs

In the original Lovaas (1987) study, contingent aversives including slaps on the leg, pinches, among others, were used. Note that the original study was done during a period of time in which the use of such techniques would have been more widespread. Lovaas (2003) states that, "The UCLA Young Autism Project no longer uses aversives, we have taken advantage of alternatives to aversives developed during and after the time of the 1987 study was completed. Treatment in the Lovaas, 1987, study took place between 1970 and 1984" (p. 390). Even with the removal of aversives, many still criticize the Lovaas approach as being too impersonal and for failing to establish a warm relationship with the child. This argument is apparently less significant for parents, perhaps as they can help ensure that the relationship stays positive in their home setting.

Litigation and Lovaas Programs

Autism was added to the list of named categories of disability in the 1990 reauthorization of IDEA. This marked the beginning of the time of rapid increase in the number of children in public schools specifically identified with autism. Yell and Drasgow (2000) studied cases of parents seeking to compel school districts to provide behavioral intervention, primarily intervention in the Lovaas model.

Yell and Drasgow (2000) examined 45 Lovaas (1987) cases between 1993 and 1998. Of these, they found that parents won or prevailed 34 times or in 76% of the cases. Procedural violations frequently caused a district to lose a case. Faulty evaluations, those done by untrained persons or those

failing to assess important areas of need, were cited as some of the reasons that districts lost cases. Inadequate IEP development or lack of trained staff also worked against school districts. But the most critical issue were the substantive violations. Here the issue was whether the IEP was "reasonably calculated" to yield educational benefit. As a result of Rowley, 1982, Supreme Court case on special education services, parents could not effectively argue for their choice of a specific methodology. The choice was up to the district—as long as the child was able to obtain some educational benefit.

Some districts lost when they failed to provide sufficient hours of programming. In other cases, if parents could show that the child had made progress with a Lovaas program and the district could not show that the child had made progress with the school district program, school districts were forced to provide the requested training. When school districts won, it was when they did things right. They had qualified persons and trained teachers to conduct the evaluations, and adequate progress data were collected.

Few local or state educational agencies in the United States consider providing EIBI programs reasoning that the costs associated with such programs are prohibitive and they are typically not obligated to provide such services. But support is growing. Mayerson (2003) writes, "Today, by reason of fiscal, public relations, and other related concerns, relatively few school districts in the nation are willing to run of risk of being perceived as openly anti-ABA" (p. 369). Some charter schools in a few states, such as Florida, seek to provide intensive behavioral programs within the existing funding arrangements. A large number of new schools have been established to offer a behavioral intervention model for young children with autism. Many of these schools are started by parents or parents in partnership with professionals. Their enthusiasm for behavioral intervention should not be ignored. These choices do not follow the major professional trends, in so far as the children will be segregated rather than included for some phases of the program and they will rely on teacher-centered discrete trial and other nonnatural forms of intervention. But they do represent the voice and choice of many well-intentioned families.

Guidelines for Parents and Professionals for the Selection of Early Intervention Treatments for Children With Autism

Several authors have presented guidelines to help parents and professionals select effective interventions for young children with autism. Heflin and Simpson (1998; as cited in Simpson, 1999) provide five key questions to ask when considering intervention decisions for children with autism.

1. What are the anticipated outcomes of a particular option; are they appropriate and meaningful; and do they match a student's needs, including his or her individualized educational goals and objectives?

2. What are the potential risks associated wit the use of various interventions, including health or behavioral risks for the student; quality of life for the child, his or her family and the school personnel involved in the intervention; and implications for the child and family if the treatment fails?
3. How will the option be evaluated; how often will the effectiveness of the intervention be evaluated; and what criteria will be used to determine if a treatment should be continued or changed?
4. What proof is available that the option is effective, such as quantity, quality, and variety of sources attesting to the effectiveness of an option; whether information regarding an intervention is published in peer-reviewed journals; and whether the validation is primarily of an empirical type or drawn from personal testimonials?
5. What other options would be excluded if a particular option were to be chosen (i.e., how the selection of a particular option will have an impact on whether other options can be used). (p. 220)

Green (1996a, 1996b) additionally calls for consumers to carefully appraise the types of evidence that may be offered in support of claims for autism treatment effectiveness. Parents and professionals should, according to Green, exercise a high degree of discernment when a treatment is supported by highly subjective evidence and little or no objective evidence. Green concludes her advice with, "The more remarkable the claims about a treatment, and the more profound their implications, the more rigorously the treatment should be evaluated (Wolfensberger, 1994)" (p. 26).

Future Directions for Early Intervention for Children With Autism

Research Directions

A great deal is now known about how to conduct highly effective early intervention for children with autism. As has been noted, a major challenge is mobilizing the social policy apparatus to see that all children with ASD are provided with appropriate intervention and that this early intervention is, especially for the youngest and Part C-eligible children, fully in keeping with the wishes of the family. Wolery (2000) offers commentary on intervention that may well set the stage for future investigations and provides a well-heeded note of caution. He notes that for those "effective programs we cannot describe their active ingredients" (p. 380). Kasari (2001) reiterates this viewpoint. And due to the lack of good program evaluation data in autism intervention, "empirical comparison of programs is premature" (p. 380). Wolery then goes on to offer five specific research areas.

1. Test treatments for children under 30 months of age.
2. Focus on the specific methods required for good outcomes.
3. Seek to understand the relationships between behaviors and determine which may serve as the basis for others.
4. Examine conditions relating to what to teach and when to teach it.
5. Seek to gain "an understanding of the demands and expectations of different environmental activities and routines to define skills to target in those situations to promote competent performance and learning." (p. 380)

Many of the questions that need to be answered will be somewhat more difficult to answer than they might have been in the past. For example, with Lovaas (1987), in the attempts to replicate the original program, the use of mild aversives is no longer acceptable, thus making a direct replication impossible. The use of the double-blind, experimental, and placebo control groups, the gold standard in many medical research designs, would now be dismissed as harmful to the children under any no-treatment condition. Consider that good research practices in human services are increasingly guided by some of the core values of positive behavioral support. Here we see an appreciation for sound research methodology, but a distinct move away from research methods that seek to artificially isolate effective components and which rather embrace the complexity of behavior change in the natural settings. It may be that a "show down" among rival approaches is never to be completed. But investigation of effective treatments with the results of these investigations put before an eager parent and professional community will continue to drive the search for evermore effective interventions.

Funding for Early Intervention in Autism

Program models and supporting technologies have been developed. The problem is that the level of intensity called for is very costly. According to Lord and McGee (2001),

> "It seems clear that the treatment costs for children with autism—sometimes amounting to $40,000 to $60,000 a year—lie at the heart of the many disputes between parents and school systems, with the schools trying to reduce their financial obligations while still providing appropriate services to the child and family." (p. 182)

Unfortunately, the standard for "appropriate" educational services, as a result of the Rowley case, is well below what is necessary to provide the interventions known to be most effective. These costs will be high whether the child is in a school- or clinic-based program or in a home program. In addition to the direct costs are the costs of teacher and therapists training

and possibly facility. The IEP or IFSP is the tool designed to assure the family that children will have their special education needs met (Dobel & Vanaman, 2003), and this can become the battleground. From the standpoint of a parent, obtaining what is needed in order to have a quality program for *their* child is the objective. But in a context of widespread information about effective early intervention programs and scant resources for such programs there can be little doubt that litigation will continue. Such litigation is a heavy burden on the resources—financial and emotional—of the family and on the educational and early intervention system resources. More litigation is not the answer.

Coordinated responses to the funding dilemma are needed. Lord and McGee (2001) recommend:

> That coordination across services and funding at federal and state levels should be encouraged through several mechanisms: the creation of a federal joint agency task-force on autistic spectrum disorders; state monitoring of coordination among service delivery systems; minimum standards for personnel in educational and early intervention settings for children with autistic spectrum disorders; and the availability of ombudspersons within school systems who are knowledgeable about autistic spectrum disorders and are independent of the school program. Coordinated, systematic strategies should be developed to fund the interventions that are necessary in local communities for children under age 3 years and in local schools so that this cost is not borne totally by parents or local school systems. (p. 7)

Only by means of well-coordinated approaches will the special and expensive needs of young children with autism be met. Parents should not be expected to carry the heavy costs, although many now do, and schools and early intervention agencies will simply not be able to do so. These issues are by no means unique to the field of autism.

Due to the unique characteristics of children with autism (Rogers, 1998), these children, when provided with optimal programs, can make impressive progress. A new funding agenda is needed based on sharing information about the impressive results of skillful, intensive early intervention. How can this information be shared to affect major changes in policy? Meisels and Shonkoff (2000), writing on the topic of early intervention for all children with disabilities, note:

> It is the mission of early childhood intervention to help young children and their families thrive. The fundamental challenge that faces early intervention services is to merge the knowledge and insights of scholars and practitioners with the creative talents of those who design and implement social policy initiatives and to invest the products of this alliance in the future of our children and thereby in the well-being of our society as a whole. (p. 3)

The autism community must influence the policymakers, and one tried-and-true method of doing this is by an alliance with families. Dawson and Osterling (1997) have suggested that investigators in autism intervention become "more effective communicators of our knowledge to the general public in order to garner their support"(p. 323). Taking a cue from their suggestion, it is now time for all persons concerned with the lives of children with autism and their families to bring these exciting developments in effective and intensive early intervention to the attention of the public.

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Chapter 7

School and Parent Partnerships in the Preschool Years

Judith S. Bloch
Joan Weinstein
Martin Seitz
Variety Child Learning Center, Syosset, New York

INTRODUCTION

Parents of children with autism tell us that the gap between their expectations of family life and their realities are at first irreconcilable (Greenfield, 1972; Naseef, 2001). Although parenting often begins for most of us with too little training or preparation, families that include a child with autism are certainly not ready for the impact and changes that will take place in their lives. With rare exceptions, these children are part of families who initially do have not the knowledge, skills, or support systems to help them deal with this challenge (Moses, 1987).

Classification and enrollment in a specialized facility serving children with learning, language, and behavior problems, including autism, create a 2-year opportunity to intervene with the child and also to provide parents with services that will promote their understanding and effective involvement in their child's education and development. With these goals in mind, the sharp division (sometimes seen in settings for typical children) between the responsibilities of the home and those of the school is not appropriate. An approach that reflects an appreciation for both systems, the central role of the family and the role of the professional in the preschool, is more likely to achieve these objectives. In this approach, an interactional process is created between the home and the school (interdisciplinary team) where social workers (often also team leaders) carry responsibility for the link to the

family. This Home/School Collaborative Model (HSCM) approach is based on evidence that child development, family resilience, and competence are most effectively promoted through collaborative efforts.

IMPACT OF CHILD'S DISABILITY ON THE FAMILY SYSTEM

Families rarely move with tranquility from ones with well children to ones that include an autistic child. Planning for parenthood and anticipating the birth of a child, or adopting and adding a child, are major developmental milestones in family life (Minuchin, 1974). With parenthood come aspirations for the family; and dreams of love, security, and achievement. The plan is for a healthy, happy child. The expectation is that the child will be an asset, although the specific form of this fulfillment depends on individual parental needs and fantasies. For many, this is a critical way to meet their need for purpose and responsibility (Carter & McGoldrick, 1989; Naseef, 2001; Satir, 1967).

The birth of any child changes the marital dyad, but the usual stresses accompanying change are exacerbated when a child's disability requires a special kind of care. The extraordinary demands of daily life with a young, autistic child can challenge and decimate the most competent parents. Basic routines are unlikely to be in place. The child's eating, sleeping, toileting, dressing, and play-time activities require frequent attention and skilled intervention. The child's inability to occupy himself and his behavior patterns, both inside and outside the home, tend to limit and interfere with the usual course of family life.

Although all families are different, we have seen some in which the relationship between husband and wife becomes tense and joyless. A mother who cannot successfully comfort or control her child's behavior may experience intense feelings of impotence, incompetence, and even anger at the child. Sometimes, mothers may react to their own feelings of distress by withdrawal and depression or become *consumed* by efforts to meet the needs of this child and respond in ways that exclude other family members. Fathers can become angry at their wives and resent their preoccupation with the child. In other families, fathers may react to their own hurt and disappointment by disengaging from parenting and focusing all of their energies on work and their obligation to meet their financial responsibilities. Sometimes the child becomes a symbol of joint failure. Weary adults, drained by powerful emotions, may see family life disintegrate and change in ways they find difficult to tolerate.

Self-esteem and image, parental expectations, and dreams are threatened by the presence of the child's impairment. The pain and disappointment that are generated, especially at the very first phase when parents first

recognize the possibility of disability, may precipitate a crisis. Reacting to the *real* can be problematic. The internal and natural resistance to this unwelcome change of status evokes a family maelstrom, as primary parental hopes are threatened by the child's impairment. Many families seem unable to cope. Parental behavior, at this point, is often characterized by anxiety, uncertainty, and even anger. The intensity of these initial reactions sometimes causes clinicians who are brought in to evaluate the child to question the capacity of such parents to nurture their child. Decades ago, some clinicians mistakenly concluded that the child's behavior was the product of poor parenting instead of the cause of distraught reactions (Bettelheim, 1967).

It is helpful in this connection for clinicians to consider that oftentimes parental reactions to the birth (or later identification) of a child with a disability is similar to reactions described in the *Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR*, 2000, 309.81 Posttraumatic Stress Disorder):

> The essential feature of Posttraumatic Stress Disorder is the development of characteristic symptoms following exposure to an extreme traumatic stressor involving direct personal experience of an event that involves actual or threatened death or serious injury, or other threat to one's physical integrity . . . or a threat to the physical integrity of another person. . . . The person's response to the event must involve intense fear, helplessness, or horror. . . . Diminished responsiveness to the external world, referred to as "psychic numbing" or "emotional anesthesia," usually begins soon after the traumatic event. The individual may complain of having markedly diminished interest or participation in previously enjoyed activities, of feeling detached or estranged from other people, or of having markedly reduced ability to feel emotions (especially those associated with intimacy, tenderness, and sexuality. The individual may have a sense of a foreshortened future. . . . (pp. 463–464)

These parental reactions that professionals observed sometimes led them to unfortunately and mistakenly conclude that such parents were irrational, dysfunctional, or part of the problem.

It is not unusual, perhaps even *typical*, for parents to react in this *abnormal* fashion to this life crisis (Frankel, 1963). It is understandable that parents who are threatened with the loss of their parental dream may at first try to deny the presence of the problem or tend to minimize the magnitude of the disaster. It takes time to come to terms with changed life circumstances and to deal with grief. Denial, at this stage, may be necessary for some parents. It can help them maintain their personal equilibrium, acquire the information needed, and make crucial decisions about services (Gallagher, Fialka, Rhodes, & Arceneaux, 2002). It is important to understand that given these unusual circumstances, the family system does not always function optimally, especially during this period of first identification, in a way that meets the needs of all its members.

PROMOTING FAMILY COMPETENCE AND RESILIENCE

No one in the immediate family escapes the chronic stress and anxiety that a child with autism generates. Almost always, especially in the early years, family life revolves around, and is planned around, this central concern. The intensity of despair and turbulence in the household has an impact on even the most stable families. Each member, in turn, responds to this ongoing state of distress, overtly or covertly, with reactions and coping mechanisms that are functional and adaptive, or limiting and problematic. Only in part are these responses shaped by personal and family attributes. "Many vulnerability or protective processes concern key turning points in peoples lives, rather than long-standing attributes or experiences . . . " (Rutter, 1987, p. 318).

According to Rutter (1985), protective factors include "influences that modify, ameliorate or alter a person's response to some environmental hazard that predisposes to a maladaptive outcome" (p. 600). Three major strands are thought to characterize resilience. These are: coping strategies; recovery in response to trauma; and "processes that moderate the relationship between stress and risk, on the one hand, and coping or competence on the other" (Smith & Carlson, 1997, p. 236). An approach that promotes resiliency recognizes the family's need for a support system, both at home (marital or partnership dyad) and in the larger community, that provides opportunities to network with others in similar circumstances. Assistance in the acquisition of "planning skills in making choices" (Gitterman, 2001, p. 27), a necessary empowerment skill, is linked to professional services that will increase parental knowledge and personal control.

Life circumstances often provide protective processes that can reduce the impact of trauma or risk factors on individuals and families. Constitutional endowment, personality and ego strengths, a loving and supportive immediate family, extended family, friends, and the availability of professional services may serve as mediating mechanisms resulting in resiliency and coping. However, the birth and subsequent care of an autistic child represent the kind of trauma where these protective factors, although present, may easily be compromised. For the parents, their inability to control or comfort their child and the realization that a less than perfect child is in their life may be experienced as a personal failure.

Even at a time of increased blending of gender roles in our culture, the mother's self-esteem may sustain the hardest blow because of *poor achievement* in motherhood. Her inability to teach, comfort, or control her child's behavior can reinforce her perception of failure. Some husbands and fathers may cope with the trauma by distancing themselves from the home and placing all of their energies into occupational activities. Their self-esteem may be sustained by success at work; their underlying unhappiness or depression

may be less apparent. Although the presence of a *well sibling* in the family may serve as a kind of *balancing* source of pride, it can also impose a burdensome responsibility for achievement on that child, unintentionally minimizing their struggle and pain (Bloch, Margolis, & Seitz, 1994). On the other hand, many siblings acquire personal strengths and skills as they learn to cope effectively with stressful events at home that serve them well in the larger community and in career choice.

The comfort and support usually available from friends and the extended family may also be compromised in this kind of situation. Mothers, in particular, may feel embarrassed to have friends know about their autistic child, assuming that they would not understand and would not be empathic. Feelings of envy and recurring pain created by the observation of other better-endowed children, at play, or achieving age-appropriate milestones can result in the avoidance of friends, social community events, and subsequent loneliness. Even grandparents are sometimes viewed as a source of additional stress rather than as sources of support and love. For fear that they will have been terribly disappointed, the secret of the autistic grandchild is sometimes kept for as long as possible.

In addition, the external resources afforded by the professional community may not always function as a completely protective factor. Paradoxically, as an array of professionals such as teachers, language therapists, occupational therapists, social workers, psychiatrists, and psychologists offer, or, in fact, serve the child, the risk factors for parents may actually intensify. The frequent reliance on *experts*, their guidance and skill, and even on the subsequent improvement of the child in response to therapies, although helpful, may also serve to undermine the confidence and diminish the self-esteem of their parents. Although this expert input is essential, it may unintentionally contribute to the parents' perception of impotence or incompetence. The need to negotiate with professionals regarding services for their child may intensify their feelings of loss of control and decision-making authority (Dunst, Trivette, & Deal, 1988). The child's disability and extraordinary need for attention and care and the parental tendency toward isolation, chronic anxiety, and the distress regarding the reduction in personal and parental autonomy all contribute to an increased risk of family disequilibrium (Vigilante, 1983).

Reducing the impact of these risk factors is possible through the introduction of mediating mechanisms in a timely and appropriate way. "An 'inoculation' against stress may best be provided by controlled exposure to the stress in circumstances favorable to successful coping or adaptation" (Rutter, 1987, p. 326). Germain and Gitterman (1996) suggest that "all people have strengths and resilience, although for some these strengths have been dampened by circumstances. Practitioners must identify, mobilize and build on people's strengths and resiliency" (p. 22).

MUTUAL AID AND/OR COUNSELING: INTEGRATING BOTH

Maladaptive family patterns may emerge for reasons that were already described. Yet offers to help in the *old traditional* ways are usually not acceptable or useful. Parents seeking a good preschool education and intervention for their child do not perceive of themselves as clients. Despite the intensity of their emotional reactions, or conflicts in primary relationships, parents may distance themselves or become angry if it is assumed they need therapy or require counseling (Rimland, 1965). An appreciation of the volatility of parental feelings combined with the pressing need to acknowledge and address specific problems in family or child functioning may create internal conflicts and pressures for staff and cause some outreach hesitation. At this time, sensitivity both to parents' needs and to their rights to decide what kind of help they wish may facilitate collaboration.

In order to promote adaptive patterns, or prevent or reverse dysfunctional behavior, it may be necessary to reorganize the approach to parents; to modify the preschool and professional service delivery model. An empowerment perspective (Dunst et al., 1994) that supports linkages between home and school (Bloch & Seitz, 1985) creates a model that is effective, especially when there is frequent interaction between settings, goal consensus, and collaboration. In this ecological approach (Bronfenbrenner, 1979), a system of support different from conventional offerings is put in place because it views parents as participants and partners rather than as clients. As Froma Walsh (1998) states: "... the same stressors can lead to different outcomes, depending on how a family meets its challenges. A core conviction in a family resilience approach is that there are strong advantages to family members' working collaboratively on finding solutions to shared problems" (p. 25).

PROMOTING A MUTUAL-AID NETWORK

A mutual-aid network is facilitated by the availability of a parent lounge; a gathering place where parents can make new friends; network; find respite, information, and comfort; or simply relax. A new source of support (parent to parent) with more information and recreational diversion is likely to emerge as parents meet others with autistic children, expand their support system, and benefit from the advice that is often unavailable from the usual sources (family, friends, and popular press). Whenever possible, the lounge can be enriched by the addition of a specialized library with readings on autism and toys for younger children. Informal exchanges among parents or with staff may prompt some to join parent education and training groups or

use other counseling offerings. The lounge makes available many additional entry points into the family system. At the same time that these ongoing, unscheduled, and informal contacts continue, parents can be approached as partners in the education and socialization of their child.

New ways of addressing family needs are created in this way without alienating parents. Parents may also be given opportunities to observe their child in the classroom and in therapies. Demonstrated interventions through one-way mirrors and intercoms are ways to help parents learn, without conferring client status. At the same time, the dialog that is generated between the professional staff and the parents as a result of shared observations is expanded. *Exposure* of staff practice that leads to follow-up discussions recognizes the value of parental input and subtly changes the balance of power.

Although increased interaction among families and staff provides more opportunities to expand and enhance the nature and quality of supportive exchanges, it also introduces the potential for problematic exchanges. It exposes *fallibility*. Flaws or limitations in professional competence or in the service delivery system are more likely to be noted when parents are encouraged to observe classroom activities and therapy sessions. A strenuous effort needs to be made to avoid any unnecessary conflict between the informalities: the exposure of staff practice, the functions of the new structure, and the increased presence and power of parents. However, in this model, differences between consumers and providers are unlikely to be totally prevented. It is better to create an environment where disagreements are to be expected, accepted, and addressed. What is important is an established structure in the school for conflict resolution and a functional experience for parents in the acquisition of advocacy skills.

ESTABLISHING A FAMILY-FRIENDLY ENVIRONMENT

A HSCM is based on the assumption that parents are best able to identify and articulate their own needs and should share responsibility with staff for problem solving. In effect, a preschool needs to create a group culture based on democratic values with the predominant parental role as team member, not as client.

This gestalt recognizes:

- The primacy of the family
- The impact of a child with disabilities living at home
- The value of a system of linked and integrated professional and parent services with responsibility carried by both
- The value of an interfamily mutual-aid network

This approach to families is supported by the New York State Education Department (2001), which approved the Autism Program Quality Indicators (APQI) in an effort to identify "benchmarks of quality programs that result in successful outcomes for students with autism." In this guide, "Parents are recognized and valued as full partners in the development and implementation of their children's IEPs" (p. 4).

A MODEL OF STAGES OF DEVELOPMENT IN WORK WITH PARENTS

The Initial Stage: Establishing the Partnership

Although families differ greatly in their circumstances, in coping abilities, and in their readiness to make use of specific offerings, it is possible to make some generalizations. A family-friendly environment is more likely to promote professional collaboration and is most important, especially at the point of entry. Many different kinds of experiences may be offered at this stage, starting promptly as close to the child's beginning date as possible with a series of evening orientation meetings for all entering parents, which gives parents information about the preschool program, their opportunities to participate, and assurances that their children are in competent and caring hands—in a safe place.

Orientation sessions tend to attract a large majority of both fathers and mothers of newly enrolled children. Families want to know how their child's preschool operates, what they can expect, and what is expected of them. A designated staff member needs to be responsible for providing this information, for initiating a relationship, and providing a sensitive and responsive reception that encourages parental involvement in their child's program. Evening sessions should focus on beginnings for both the parent and the child in the program. The child's initial task is to separate from home and adjust to school. Parents may assist the child to begin, by sharing information about food or toys that comfort, or activities and interactions that are likely to create distress or exacerbate initial reactions. Including parents in the planning of this critical first entry step will ease the child's transition and, at the same time, empower the parents and demonstrate the value of collaboration.

Orientation meetings introduce the HSCM and the team concept. These beginnings can provide parents with some relief from their tension and anxiety as they begin to see the preschool's potential for remediation and the opportunities for their input and involvement. When a large orientation group segues into smaller groups, parents will also have an opportunity to meet others with similar concerns, in the same situation. Beginning discussions and opportunities to share experiences provide a preview of the

group experience. In this way, parents are familiarized with the value of group discussion and the school system—the way it works, the concept of a home and school partnership, and the interdisciplinary team.

Entering the Work Phase: The First Collaboration

A major stress point for most families is the classification process (Bloch, 1978) required to establish entitlements and to access services. There are many uncertainties that attend this process. Characteristically, this stage of first identification and the parental tendency to be secretive keep others in the family's extended circle in ignorance and may deprive parents of needed emotional and social supports. Most parents are likely to struggle privately, alone, with this newly perceived possibility: Their child may have a handicap. Even as parents arrange for their child's evaluation, there is hope mixed with resistance to the possibility of a confirmation of handicap; especially one that may be long term or chronic.

After the evaluation, classification, and determination of the need for a preschool placement, preparation of an assessment, which produces a comprehensive baseline needed to set instructional goals and interventions, is required. A process that includes parents will also increase their understanding of their child's special needs and strengths, help set functional priority goals at both school and home, and begin the HSCM process.

Shared assessment is the first formal collaboration between the parents and the interdisciplinary team and is a key aspect of the collaborative model. *The Five P's (Parent/Professional Preschool Performance Profile)* is one such assessment instrument (for children 6 months to 5 years old with learning, language, or behavior problems). Parents and teachers, separately and independently, observe and rate the child in the home and preschool. In this approach, parents share responsibility for assessment with the team. Assessment produces a comprehensive picture of a child's performance across all major domains of development (Bloch, 1982).

An assessment should integrate data from parents and teachers with clinical tests and observations. In this way, the value of parental and teacher input is recognized in the establishment of a child's performance baseline, which helps set functional learning objectives. Assessment, goal setting, and intervention plans are to be linked. The process sets the stage for an ongoing alliance with parents that can help overcome patterns and perceptions of powerlessness. Knowledge is power. The assessment leads to the identification of a child's strengths and gaps or delays in achieving milestones anticipated at specific ages. The comprehensive profile that is produced serves as a tool in parent education and promotes the development of realistic behavioral expectations. Sometimes, parents will become confused when they observe splinter skills and see that their child can *spell*, memorize

books, and repeat TV programs in their entirety. A child may appear advanced and even bright for his age. Parents and their extended families may attribute greater significance to these achievements than what is warranted. The assessment process helps them expand their understanding of both the strengths and the limitations of their child's learning strategies. Including parents in the assessment process serves many purposes. It paves the way for collaboration and empowerment, increases the accuracy of the data collected (Bredekamp & Copple, 1997), and is one of the best ways to get a comprehensive picture of the child's performance in multiple settings.

Parents who participate in assessments in this way will increase their ability to:

- Systematically collect data about their child's behavior at home
- Observe and rate their child's behavior
- Understand early childhood development
- Recognize behaviors that interfere with learning
- Develop more realistic expectations for their child
- Monitor their child's progress and change over time
- Participate in team decisions regarding goals and remediations

A powerful motivation for involvement in this process is the parents' natural desire to help their own child and to identify and formulate plans that are suited to their own unique situation (Dunst, Trivette, & LaPointe, 1994; Spiegle-Mariska & Harper-Whalen, 1991; Vosler-Hunter, 1989). Parental responses to the opportunity to participate in *The Five P's* assessment indicated that this system increased their understanding of their child's development and helped them participate more effectively with their child's team (Bloch, Hicks, & Friedman, 1995).

An assessment process that includes parents supports an empowerment perspective. It demonstrates respect for parental judgment and informed decision making and choice (Bloch & Seitz, 1985). The model puts into practice Bronfenbrenner's (1979) proposals that child development is advanced by frequent interactions between home and school and goal consensus between settings and supportive linkages. Although the assessment begins shortly after enrollment and is necessary for the many reasons already cited, the process may also generate additional stress. Staff need to remain mindful that the parents new understanding may increase their anxiety.

Work With Parents: Expectations and Options

As families become more familiar with their child's disability, the research, and the *window of opportunity* in the early years, they can understandably become even more frantic in their efforts to find the most effective

treatment. Even those who are satisfied with their child's program may be tempted or driven to explore other possibilities. Considering all options for intervention, sorting out and evaluating other treatments, some of which may promise quick gains or a cure, can become a time-consuming activity for some parents. Although there are some constructs, such as early intervention and active family involvement, that appear to be common to all effective programs (Cohen, 1998; Dawson & Osterling, 1997; Wolery, 2000), the hope for a full recovery for all children on the spectrum remains an elusive goal, whereas good progress can be achieved through a range of options. There is no professional agreement on the content, type, and intensity of services that will ultimately promote significant changes (Kasari, 2002).

Although there are benefits to parental preoccupation with methodology, there are also pitfalls. Any additional drain on family resources (time and energy) has the potential to lead to neglect of personal or sibling needs and may become a distraction from the immediate work on hand with the preschool providing the program.

However, as parents are exposed to the range of interventions, it also serves to help them gain some sense of control. They have options; they can select. "It is an awesome responsibility to have the life of your child in your hands," reported one parent. For others, the search restores some sense of control and empowerment.

PARENT EDUCATION AND TRAINING: PROFESSIONALLY LED GROUPS

Receptivity on the part of parents and professionals to potential partnerships requires trust and changed attitudes (Vosler-Hunter, 1989). Some professionals will need to deal with their own feelings or attitudes that could alienate parents, especially if parental involvement is experienced as a threat to their competence or expertise. And, now a paradox. The professional *rescue fantasy*, often a motivation for occupational choice, has the potential to become an Achilles' heel. Staff skills, good intentions, and eagerness to help may interfere with parental empowerment. Parent subgroups present different challenges; for example, well-informed, outspoken parents with professional backgrounds may be intimidating, and other less well-educated, young parents may need staff to reach out to offer an opportunity that is different from earlier negative school experiences before they can become collaborators.

Because parents are indispensable team members, active partners in their child's education, whenever possible, and at the same time responsible for the needs and demands of each family member, it is understandable that families at this stage are likely to be in disequilibrium. At first, parents, especially mothers dealing with daily routines that are not in place, are likely

to focus primarily on their preschool autistic child, putting aside other family considerations. Many are eager to acquire needed new skills and meet others dealing with similar fears and problems. It is good timing to make available homogeneous groups of mothers, fathers, or parents of autistic children (with shared concerns) that can meet on a regular basis. The content issues on which members will focus will differ according to the group's priorities (e.g., bedtime routines, toilet training, language acquisition).

Parent support, training, or education groups benefit from a psychoeducational structure, one that provides both information about autistic spectrum disorders and support for parents. Parents need information in behavioral management techniques and applied behavioral analysis (ABA) that can promote learning and reinforce appropriate behaviors in both school and home. It is also important to provide information that will help parents understand their children's learning styles and strengths and their responses to the presentation of learning materials, pictures, and icons. Additionally, specific challenges, such as difficulties with generalization, socialization, and play skills, require discussion and consideration of specific intervention plans. Parents are often eager to engage in discussion and group problem solving about sibling issues as well as the impact of their autistic child on the total family system. Alumni parents who can share information, resources, and a more experienced perspective provide a highly valued addition to the parent groups.

Teaching parenting skills that will support a child's development can be very effective especially when implemented during typical daily activities and interactions at home, and parents choose what and when to learn new skills (Kaiser & Hancock, 2003). Although these groups focus on the acquisition of skills and the presentation of relevant information (e.g., the nature of the child's learning and teaching strategies), they also support the sharing of feelings and ideas surrounding the autistic child and other family members. Information about new strategies, as well as the emotional support and accompanying empathic responses from the group, promotes the problem-solving efforts and provides comfort. As one father poignantly stated at the conclusion of a group to which he came reluctantly (upon the prodding of his wife), "I really didn't want to come and initially I felt very depressed here, but I learned a lot; especially helpful was information about techniques. Even though everybody's situation is a little different, this experience helped me feel better and not so alone."

WORK WITH FAMILIES CONTINUES

After the child's entry to the program, the orientation meeting, and assessment process, parents need to be offered an array of options in both group

and individual formats to begin to deal with their social isolation, concern about their child's behaviors at home, and participation in the remediation plan. The children's inappropriate behavior and the quality of parent–child relationships are sources of great parental stress. Parent training programs that address these goals and involve parents in the change process are helpful (Marcus, Kunce, & Schopler, 1997). The transition from social isolation and loneliness to social integration can be noted in the following record.

Caren: Friends don't understand. They want to reassure me that everything is okay. You see, he likes everything in rituals. They are trying to help him accept some changes here, but it's very hard. My friend and I recently went out to dinner. She had not seen him for a long time, but she just did not get it. He's 4, but she was comparing him to her 2-year-old to normalize his behavior. Probably will be another long time before we have dinner again. I had signed him up for nursery school, but when I realized that he would have to go to Variety, I tried to avoid all my friends who would ask me about the community nursery school where all the neighbors' kids were going. However, one day, I couldn't avoid a neighbor and had to tell her. I felt very uncomfortable.

Joyce: I give myself a pat on the back for coming to Variety and for getting Eric help. I am so happy to be here. As I said earlier, leaving will be hard for me.

Leader: I notice that many of you are in different places. Doesn't it seem that way?

Barbara: Yes, we are in different places. I am very comfortable with my child's issues. I don't know why exactly, but I am not embarrassed and don't feel judged about it.

Susan: I am not so comfortable. I will go to the next park over to avoid my neighbors. I feel sad for my son, but I don't want to answer questions that people ask. I don't understand why strangers act so nosy, but I try to avoid that.

Yvonne: Well, if you are not comfortable, it is better to go to another park because your son will pick up on your discomfort.

Barbara: We all handle things differently because we are at different stages. If you prefer, the next park over, then that's okay for you.

Leader: Is it okay for you, or do you feel undercover?

Yvonne: I am not sure. I don't like the way I feel about it. I'm somewhat ashamed that I don't stay in the neighborhood.

Leader: It's a hard thing to acknowledge when one of our own children has a special need. How many of you have told your families that you come to Variety? Yvonne, have you shared that yet?

Yvonne: Well, with my sister-in-law who is in the special ed field, yes. With the others, no.

Leader: God, it's such a hard thing to talk about sometimes, isn't it?

Yvonne: (*Starting to wipe eyes again*) I can't stand the accusatory eyes of others or to hear others talking about him. They don't know how it feels. I get so angry.

Barbara: Some people go through life that way. Yvonne, I think when others are asking questions, like when they would ask why my daughter, 5 months, wore glasses, I didn't see it as malevolent; just curious.

Yvonne: Maybe for some, but not others who have no right to ask so many questions. I feel proud that I was smart enough to get help for my son when he needed it. I don't know how he will be in the future. I mean I don't worry as much as I did, but I still worry plenty.

This excerpt is from a group meeting early in the life of a group. Members are discussing similar issues characteristic of the initial phase, such as: not trusting family and friends to understand their pain and anxiety, fear of embarrassment and rejection, and efforts at coping. The leader facilitates the sharing and validates the different ways that members are coping. In this way, the leader promotes the idea of *all in the same boat*, but, additionally, introduces the group value of *acceptance of difference.*

Major adaptation tasks in the middle phase are conceptualized as follows (refer to table on pp. 258–261):

1. Transition from trauma and mourning to acceptance and adaptation
2. Transition from family disequilibrium to family balance (Weinstein, Bloch, Lichter, & Seitz, 2002)

Parents are hopefully now moving along this continuum, working toward these goals. In the process, the families' equilibrium is often challenged by their increased understanding of their child's disability and functioning as they begin to allow themselves to also understand the possible chronicity of their issue. Implications for the long-term impact on the quality of family life, adult responsibilities and relationships, and siblings become more evident and worrisome. Over time, the child's improvement, compensating strategies, a supportive network, and personal characteristics may ease the

pain in the lives of some adults and families. For others, the ongoing impact of their child's severe and disabling behavior may continue to erode the quality of family life.

Some groups will focus on key areas that change the developmental tasks families are facing in their life cycle. Special events or holidays often precipitate crises. Resources may be challenged, but appropriate and timely intervention by staff may also create opportunities for strength building and enhanced adaptation. Schools can help by providing single-issue workshops such as "Stress Management" or "Managing the Holidays." School clinicians need to remain mindful and alert to the varied ways in which these opportunities for work become evident and present themselves. Attunement to these critical moments and developmental touch points can transform parental stress and distress into strength and empowerment and family disequilibrium to family balance (Middleman & Wood, 1990). The balance between process and content (knowledge and information) always requires careful and sensitive consideration (Meyer, 1987).

Family equilibrium can be promoted by addressing couples' perspectives around their autistic child, any siblings, and their extended family. More effective intrafamily communication and collaboration may promote parental confidence and abilities; strengthen relationships, insight, and problem-solving skills; as well as help families access appropriate community resources.

A many-pronged approach to promote family equilibrium and family adaptation that responds to their diverse learning and coping styles will encourage parents to make choices. These can include membership in formalized groups; training seminars that use a psycho-educational approach, for example, understanding sibling issues and how to help; programs that use group format but are single-group events, such as Sibling Day, Grandparent Day; informal social networks forged through participation in a parent organization or a parent lounge, as well as individual counseling services, or access to other community support services. In fact, a fluid nature among the internal systems in which parents may also be informally referred by staff and parents alike to utilize various services is likely to increase and maintain family involvement. For instance, an issue may arise in a group where one member of a couple is a member, and it appears that the couple together, or even the parent and child, have special personal concerns. In these instances, a group leader will encourage a parent to tell how individual counseling helped her resolve a struggle and help refer the parent as well.

The following excerpt from a group meeting highlights parents' struggles as they move toward coping with their realities, with the group leader gently reaching to illuminate the mourning theme omnipresent in groups of parents of autistic children.

Leader: I'm feeling very touched by the sharing today. Anyone else having reactions to it?

Yvonne: Yes. It feels so good to talk. (*Others nodding*)

Caren: (*Teary now*) I guess we can come here and cry a bit on Tuesdays.

Barbara: Funny, I am sitting here wondering why I am not so affected like others here. I am not sure why exactly.

Leader: Everyone reacts differently.

Barbara: I am trying to reflect on my situation. My daughter has lots of issues. Maybe because my others are older so I feel differently. We were living abroad, and if I hadn't moved home, she probably wouldn't have gotten all the services that she needed. So, I am very appreciative of that.

Caren: I am very appreciative of the small changes. For example, I can read him a story now. I couldn't before. It has to rhyme, and then he can sit through it. Before, he just pushed me away, went off by himself. That feels so good to me now.

Barbara: I can't hold her and read to her like I could with the others. I used to rock the others and read to them. I loved that so much. She won't let me. She can't tolerate that.

Caren: You could try the rhyme books. I can recommend some to you.

Leader: Caren, that is such a nice suggestion, but I think Barbara is reacting to something more. I think (*to Caren*) maybe it feels like a loss to you?

Barbara: (*Now starting to cry*) Yes, it does feel like a loss.

Susan: It is a loss. We have had loss.

Barbara: What helps me so much is being able to reflect and discuss my daughter with people who understand, like all of you.

Leader: People who get it?
(*Nodding*)

The previous discussion took place at a meeting that had been ongoing for some time. The group members did much sharing of feelings. Individuals had begun to talk more openly about their sadness and feelings of loss and obtain some relief from such expression. The group, as a whole, had achieved a state of intimacy that enhanced its cohesion and its potential to induce changes in its members.

Middle-phase issues often include efforts by family members to reestablish good relations and balance in their lives in the face of the disequilibrium caused by the entry into the family of an autistic child. Frequently, the child's behavior produces a strain on the marital relationship. Husbands and fathers are sometimes resented and accused by wives and mothers of not helping,

although they themselves may be partially responsible for creating barriers to their participation. It is worth remembering that there is a reality to the need to anticipate and manage some of the children's behavior at home. The children's inordinate demands and volatility require finely honed expertise. This responsibility is added and in tandem with the required attention to other family members and general home management tasks. As many mothers have gained these skills, their wish for paternal involvement can be tempered with their wish to maintain control in order to promote home stability—a conflict that creates barriers to their husbands' participation.

Including fathers in as many program phases as possible, but especially the assessment process and follow-up planning meeting, may offset any unintentional exclusion (Rump, 2002). When fathers are not encouraged to participate, schools may be contributing another stress factor by placing one parent in the role of information transmitter. In preschools that are often female dominated, efforts to increase the level of comfort for fathers should be considered, and staff may need to make extra efforts by providing flexible scheduling. Arranging opportunities for fathers to meet at special events, such as fathers' evening groups or "Daddy & Me" activities, gives them networking opportunities and helps promote collaboration. Most importantly, it highlights the fathers' role in the family system and their significant place in their children's lives.

We also need to remember that mothers and fathers may move through the stages of understanding and coping with information about their child's issues on different timetables. They will benefit from support services that address and reconcile both perspectives. Sometimes, one parent may view the other as not caring when, in fact, that is their way of coping with their sadness. Engaging in a dialog with a group or couple counseling can help work toward rebuilding bridges and strengthening the home team in the service of their child. And, fathers may view their role with their children in a different way than their wives may have envisioned. They may be willing to take risks with their children that their wives resist, in the interest of maintaining stability and protecting their child. Mothers may view their husband's behavior as inappropriate, undermining their role as child expert.

In the following excerpt, most of the meeting was spent talking about husbands and fathers.

Caren: My husband goes to a therapist and is trying to change. He has to, or the marriage won't work. He is so disconnected.
Linda: My husband would be too, but I don't let him. Do you keep him involved?
Caren: I try, but he's not interested.
Linda: Did he go with you to the parent–teacher meeting?
Caren: No.

Linda: Maybe you can invite him to meet with your social worker, or to call the teacher. You can share the reports with him, too.

Leader: Caren, did you invite him to come to the team meeting?

Caren: No.

Leader: You want him involved, but you did not invite him. Are you protecting him like Susan does? I am confused.

Caren: I set him up. (*Pause*) I am angry with him, and I think I want to stay angry with him. I am angry that he can't give me more. Don't get me wrong; he is a wonderful man. If you met him, you would think he is so charming. I just wish he could go through this thing with me. I am going through it alone. I celebrate every accomplishment that Sharon makes. Having my daughter has prioritized my life, but he doesn't get it. I don't know what I am going to do.

Susan: I can't articulate my needs as well as you can, Caren. You seem clear on what you want. I don't know what I need right now, but I am going to make an appointment with my social worker. I am tired of being in the middle. It's too much work.

Leader: Sounds like you do know what you don't want, Susan.

Leader: Remember, we spoke previously that you all are going through a crisis? You liked that analogy. You all agreed it was true. During a crisis, people do not make good decisions. It is not a good time to make big decisions. People don't think very clearly in a crisis. This is a very stressful time on a marriage. It won't always be this stressful.

Susan: (*Very reflective*) It's true. Now is not the time to assess one's marriage.

Leader: Use your social worker to help get your husbands involved. It can make a difference for the family. Just having some quiet time to talk together without the children . . . with your social worker . . . we are available to you.

At times, in meetings of a Mothers' Group, the members express feelings of being overstressed and direct their anger at husbands who don't help enough. In addition to the relief they experience and the support they receive from unburdening themselves in discussion, the leader helps them do some reflective thinking. Some members become more empathic to their husbands and even consider the possibility that they themselves may create barriers to their husbands' participation. It is good when the group discussion moves from venting anger to a consideration of strategies that could improve relationships with husbands and enhance situations at home.

An additional guiding construct in work with families is the parental journey from lack of understanding to increased insight, knowledge, and skill (Weinstein et al., 2002). As families move toward the termination of their stay in their preschool program, there is an increased focus on future planning for their autistic child. The team needs to anticipate and discuss the transition as the parent groups work on empowerment of the family as an advocate for their child with their expanded knowledge of their child's needs, the educational systems, and legal rights.

All of this takes place as families face change, separating from a place of comfort and trust to embarking on new beginnings. The anticipation prompts a range of responses. For some, it is a joyous time coupled with reawakened past anxieties. For others, it is a time to reconcile hopes and dreams and continue to work through their disappointment toward greater adaptation to their child's unique abilities and needs.

In another group, a mother shares her adaptation regarding her 4-year-old autistic son as she is supported by the group:

Julie: I have changed a lot since I first came here. I have learned to be patient in this group. I guess I've come to understand that this is a journey, and I think I can appreciate and be satisfied with small steps now.

Beginnings and new relationships may be stressful, but endings and leave-taking are more difficult. Even though both sides, families and staff, know it is time, some of the old fears may surface again. As the ending time draws near, earlier anxieties often arise as well as sadness for some dreams that remain unrealized and culminate in palpable pain. For many families, it will be difficult to leave a place that has provided a safe holding environment and comfort for themselves and held at bay community eyes and judgments. One parent wrote to say:

"Those feelings my husband and I had that we were all alone and no one would understand what we were going through soon disappeared when we arrived for our first orientation meeting at the school. We found ourselves among about 100 other confused and eager-to-learn parents. After now attending numerous workshops and support groups—not to mention frequent visits to the Parent Library—I can honestly say we are different parents (emotionally stronger and more educated on developmental issues) than we were two years ago when we entered the school."

And another sent a note:

"I've come the whole circle from wanting you to get away from me—to you being so very kind—helpful, and help me through very difficult times. I am lucky you were there. What a splendid discovery. I'm glad I let you help me and Johnny."

At this juncture, it is helpful to have short-term groups focus on educational rights and advocacy as well as on transition. Selected alumni parents, ready to share their ending experiences and beginnings in new schools, will help parents deal with the change. All these combined efforts give parents opportunities to work through their separation anxieties and network with other parents. Hopefully, as one parent reported, "It is scary, but I am talking myself through it this time, using the skills I learned here. I need to hold on to my confidence."

Some parents who have struggled with their child's disabilities for several years may in their journey revisit and take stock of their value system. Time and grief work may activate earlier core existential ideas about the meaning of life and personal priorities. Many parents have reported that although their assigned path is not one they would have chosen, their individual journeys, made as the result of their experiences as a parent to a special needs child, have led to modified and clarified values. In many instances, it enhanced their own personal growth and that of their family and enlarged their world.

"I sometimes ask why me? But then I stop and realize that John . . . "

Another parent writes that:

"Joseph has opened up vistas for me that I would never have seen without him. As he scrutinizes the grains of sand as it tumbles out of a cup, or responds with heightened sensitivity to a myriad of textures in his clothes, or pauses to hear the sound of the train as it glides through the station nearby, I am reminded of how his heightened powers of observation enrich and enlarge my world. I learn to see and to feel and to hear so much that I had previously tuned out. There are so many gifts that Joseph brings to my life . . . I don't take anything for granted anymore . . . He has also impacted on my career choice. I probably would just be a regular kindergarten teacher, but with all the experiences I've had and after all I have learned from him, I needed to use that to help other children, and I now have special education credentials and help other teachers understand and work with these children."

We see many parents, particularly mothers, making career choices or changes that incorporate newfound skills and perspectives. Some parents elect to go into special education and others choose counseling where they can make a difference for other children and families.

THE INTERDISCIPLINARY TEAM

The Individuals with Disabilities Education Act Amendments of 1997 (IDEA) has heightened the field's appreciation for the work of the interdisciplinary team and the value of practice which promotes and supports an exchange of competencies among its team members. Loose boundaries

and collective responsibility enhance teamwork (McWilliam, 2000). Even though teamwork is not required by law, it is a reality in many preschools. The degree of success, whether it works badly or well, is determined by the administration, the team's philosophy, expectations, and performance. It is our purpose here to identify some key ideas and working principles that address, and may prevent, inherent problems in the design and function of the interdisciplinary team.

An interdisciplinary team is a group representing different professions organized around a problem, collaborating to accomplish a commonly agreed-upon goal. There is a division of labor as well as group responsibility for outcome. Unfortunately, it is, indeed, a rare phenomenon when the interdisciplinary team functions as just described. Often the term interdisciplinary team is a euphemism for an autocracy dominated by one discipline, or, at the other end of the continuum, an anarchy where everyone on the team does his or her own thing. The former is most characteristic of the medical setting, and the latter is often the form taken in the traditional special education setting. However, the recent growth of preschool special education programs offers a new opportunity for a more successful interdisciplinary education team.

Incidentally, it should not surprise us that the use of the interdisciplinary team has often been problematic in many settings that embrace the idea. It appears that the integration of staff efforts around a common problem is glibly talked about; its complexity, not well recognized. After all, how can staff members who differ in professional training and personality learn to function as an integrated unit? Three interrelated issues to be discussed are: (a) an overall philosophy, (b) leadership, and (c) confidentiality.

An Overall Philosophy

The basic premise underlying the preschool interdisciplinary team is that no one discipline can provide all that is needed to promote the development of both the child and the family. The team collectively needs to be viewed as the single major instrument for change. Staff members with particular professional backgrounds provide the skills needed to achieve this goal. Each team member has a major responsibility to contribute data in her area of expertise as well as to participate in team decision making. Simply put, the team may include all or some of the following: a special education teacher, language pathologist, psychologist, social worker, occupational therapist, physical therapist. Each is required to carry out her role in accordance with the child's Individualized Education Program (IEP) and an overall plan developed by the team as a collective product. Furthermore, the overall plan has to be the result of ongoing collaboration with parents through direct contact with a designated family liaison.

Social workers or psychologists responsible for work with families need to share a family perspective with the team and identify those accommodations that are most likely to promote collaboration. Many preschools may not have such a staff. They will need to designate other team members who can carry this responsibility and who appreciate the value of parent involvement (Vigilante, 1990).

An empathic understanding of the family's trauma is essential, but not sufficient. Familiarity with the steps in the parental struggle to accommodate are also required. Core constructs include an appreciation for the following:

- Family system; its value system and culture
- Parental and family journey, which may proceed differently for each member and from family to family
- Pacing and judgment of staff to set performance expectations

Periodic user evaluations, or input from parents, can identify useful program offerings and interventions. Helping families improve the quality of life for each member in the face of a chronic and long-lasting disorder calls for a unique blend of professional skills, attitudes, and understanding (Walsh, 1993).

Each team member informs and describes to the others the nature and implications of behavior from his or her professional perspective, identifies their therapeutic intervention, and suggests appropriate instructional objectives and adaptation for follow-through in other areas. Each member is also responsible for incorporating an understanding of the family and its capacity to collaborate in the education of their child. In this way, the team tasks of regular assessment, review of priorities, and coordinated interventions are maintained.

Collectively, the team is viewed as the major intervention instrument. The team shares professional responsibility regarding decisions affecting the child and family. It provides a professional system of checks and balances; it deals with the conflict and competition that can develop in an interdisciplinary system. It provides a system for mutual emotional support to its members to enable them to deal with the stress and difficulties that are sometimes a part of work with autistic children and their families.

Leadership (Role of Team Leader)

The interdisciplinary educational team is a *group* and, as such, it constitutes an interactive and interdependent entity. As with all groups, leadership is a key function for effective work. The team leader should be skilled and experienced, respected by others, and may be selected from any discipline.

The position requires an understanding of the way child development is shaped by both biology and experience and the course of development altered by the nature of interactions with caregivers.

Task accomplishment refers to the responsibility of the team to collect data and to engage in problem solving and decision making. The team leader helps the team make decisions. More specifically, the team leader needs to be able to make demands for data, evaluate it, and request additional information when needed; to identify problems and arrive at recommendations (interventions) in a timely way. The team leader helps the team maintain both a child-focused and a family-centered approach as members consider their discipline's specific input (Dunst, 1995). A plan is then articulated which is the result of their collective thinking.

Although the role of team leader is to carry responsibility for the work of the entire team, it is apparent that the performance of each team member is also of concern. When each member is making good contributions and the team is functioning well, there is no issue. But, there will be instances where there is difficulty and a team member may not be contributing necessary data, may be having problems with other team members, or present troubling personal behaviors. In those instances, the team leader may need to enlist the help of a supervisor or the administration.

Group maintenance, or a concern for the emotional needs of team members, is another leadership task. A well-functioning team provides a system of mutual emotional support for staff members that enables them to deal with the stress of the work and to tolerate the tensions that may arise from occasional disagreements among members around goals and methods. The team leader can help to develop a good working climate by modeling behavior. The team leader can establish norms of behavior and feelings of trust, so that team members can share what is going well, what is not going well, and then proceed undefensively with good problem solving. Decisions become the products of member thinking and cooperation related to skills and experience.

Potential Problem Areas

The role of team leader as an ideal type and a system with faults and potential problems have been described. Within the discussion, certain obstacles to effective functioning were identified, and some suggestions for handling were offered. The next set of ideas are offered to sharpen and reinforce but not dull the optimism that the role of team leader can carry effectively. Concerns that would impede good team functioning include the following:

1. Leaders who are not fully aware of their responsibilities
2. Members who engage in blaming and protecting

3. Members who act as free agents and ignore the constraints that team decision making imposes
4. Teams whose roles and responsibilities are usurped by an intervention designed outside of the team, without team leader knowledge or input

Confidentiality

Communication among team members is crucial for obvious reasons—much of it concerns sensitive information. Such material needs to be handled in both an integrated way and respectfully. Concerning the former, individual team members cannot engage in separate planning and interventions divorced from their roles as members of the interdisciplinary team. No team member may act as a free agent. As to the latter, the respect for confidentiality needs to be extended to prevent hallway chatter and carelessness with written material.

COLLABORATION UP CLOSE

It is often with great trepidation that parents of young, nonverbal children allow them to attend a school program away from the protection provided by the home. Parents worry about the safety of their very vulnerable children and the need to bridge adjustments, because they typically have difficulties with transitions. It is useful for parents to have contact with staff prior to the child's entry to the school. They can participate in plans for beginnings.

Parents provide the expertise needed to ease the child's adjustment by sharing information about specific toys or activities that they enjoy and interventions that could help staff comfort their child if necessary. School staff, in turn, make some suggestions to parents that could help with the transition. They might even send home a picture of the teacher, school building, classmates, or special school toys that the parent can introduce to their child.

When children begin school, a dialog between parent and staff (teacher and social worker) can help time the separation process. This can be swift or slow, paced with parents cuing staff ("When she gets upset, you can give her the tape recorder with her special tape to soothe her.") or staff cuing parents ("Now that he seems comfortable with staff, perhaps you can still be in class but make yourself busy, bring a book, and become engrossed in it."). Sometimes, a book for the parent to read to the child at home, or school toys sent home for the child to become familiar with, in the safety of the home, will ease the transition to school. All of these beginning activities model the value of home–school collaboration for the parent and their key role in their child's program.

Although the teacher and speech therapist may identify language goals that are linked to the child's developmental level and a hierarchy of language goals, a parent at an initial meeting may sometimes request that staff work on the word *Mom* as a first goal. Whereas that may be at variance with the thought-out plan of the team, it is often very valuable to hear and respond affirmatively to the parent's request for so many self-evident reasons: The parent feels listened to and respected; and, if the child is able to approximate this goal, it can have an enormous impact on the circle of affect between the parent and the child.

Sometimes parents may select goals that are quite at variance with the professional team. Even at these times, efforts should be made to give consideration to parent goals and also to engage parents in a discussion of the team's perspective. Hopefully, this will lead to some negotiation and a meeting of minds. This may happen in a situation where parents might select to have their child toilet trained at a point where staff feel the child does not yet have the necessary prerequisites, or the stress of beginning such a program is untimely and will impact on the acquisition of other priority skills. Often staff and parents can come to an understanding and an agreement on a timetable and introduce some beginning steps in the toilet-training process, but not yet the full program.

Parents are encouraged to work on home goals that may impact on family functioning (going to sleep routines or mealtime behaviors) that can utilize techniques from school. They are also encouraged to use natural opportunities to reinforce school learning (e.g., bath time: "point to eyes," "point to nose," pouring water down: "down") . Wherever possible, interventions are embedded in the child's usual activities using strategies that are compatible for a family, feasible, and meaningful. Although these are globally identified in the parent–teacher meeting, they are more finely tuned for each specific family with the appropriate staff person. Perhaps Dad can engage his child using a gross motor activity playing "Stop and Go," or rolling a ball and working for eye contact and language approximations. It is crucial to initiate a dialog to discuss the family's capabilities, so they can join in titrating home tasks to their limits. It would be easy to distribute a whole laundry list of home programs indiscriminately, but for many families that might feel overwhelming and little would be accomplished for the child or the family. Working with the knowledge of the child and the pulse of the family supports the promise of progress in school and at home. It is helpful to provide written team recommendations for the home that will promote the mastery of goals through interventions that take place during the ordinary routines of daily living (e.g., bath time and dressing activities can reinforce language goals).

What is important in making collaboration with parents work are activities of the team that do not undermine parental confidence. As was discussed

earlier in this chapter, the protective factors afforded the family of the autistic child by the experts may be compromised even as the child makes progress because it may make the family feel inadequate to the tasks involved in raising their child. The team needs always to keep before it the realization that it is usually the Mom who is the main caregiver and educator. Any process that does not result in her increased coping abilities and resiliency must be considered a failure.

As team members learn to trust each other and share not only information but also feelings, opportunities to learn from each other emerge. The children's difficult behaviors and the parents' level of pain and frustration, often create a heightened level of stress for team members. For example, a teacher who has spent an exhausting day with a youngster may receive a note from a parent suggesting that the child's needs were not fully addressed: "You sent home blue mittens, but Johnny wore red mittens today." The teaching staff may react to the implied blame and feel: "She doesn't know how hard I am working with her child." She needs a place to express her distress. The team provides this opportunity. Members are able to validate a staff member's feelings; help her try to depersonalize, step back, and begin to understand that what appears to be a criticism may really be a reflection of parental distress; simply one way parents sometimes express their disappointment.

The work of teams requires a generous blending of each discipline's unique expertise. It is coupled with the team members' ability to monitor their own egos and integrate information through the lens of another discipline. As an example, consider a team's efforts to develop a feeding program for a 3-year-old autistic child who was solely eating Stage 1 baby food, refusing solid food, and drinking from bottles. At home, he was propped up on a sofa, coaxed to accept pureed infant food, and then willingly allowed himself to be spoon-fed dessert (baby food fruit). In school, he initially refused to eat the baby food offered to him by shaking his head back and forth to indicate *no* and crying. At first, the classroom staff followed the parents' lead and mirrored the home pattern. As the team met and reviewed this child's plan, they knew they needed to reconsider the priority goal and intervention plan. Each discipline needed to reassess the child's eating behavior and skills and develop discipline-specific goals. The team would then review these, synthesize the information, and reset the priority goals and plan.

Feeding issues are complex. Eating is such a basic life-supporting function that it appropriately stimulates a high degree of both staff and parent worry. Staff and parents met to review basic information, to address medical concerns (e.g., if there had been a barium swallow test, to see if the child was deemed underweight by the physician). All underlying and critical medical concerns had to be ruled out or identified. The evaluation showed that the child was not medically malnourished. Although his eating profile was significantly delayed, his behavior had not produced a medical crisis.

In this situation, each discipline had unique contributions to make: to provide information, to propose interventions, and to monitor and adjust implementation and methods of the treatment plan as needed. The teacher observed the child's eating patterns throughout the school day, at snack time and lunchtime, and monitored the behavior of her staff who were often eager to be the first ones to get the child to eat. She had ample opportunity to observe the child's response to food presentation and the effectiveness that withholding of attention during the eating process had on his behavior.

The speech therapist and the occupational therapist observed the child both in individual sessions and in the classroom group. They prepared their assessments of feeding and oral-motor functioning in order to evaluate the child's physical abilities (to manage food-tongue movement, ability to chew, and overall tone) (Case-Smith & Humphry, 2001). The occupational therapist also assessed the child's hand functioning and ability to use his hand for self-feeding.

The social worker met with the family to engage them in the partnership and in problem-solving concerns about their child's eating behavior. She needed to both obtain feeding history and information and understand the parents' perspective and approach. She explored with the family their ability to work on a program, considered their cultural values, extended family issues, and the role and nature of each parent's interaction with the child.

In this situation, each discipline provided information, listened to each other, and considered the information. Then the team developed the initial treatment plan. Based on assessments and information shared across disciplines, an understanding of the child's eating patterns emerged. His behavior was best explained by a learned behavioral response to food presentation, secondary to oral-motor immaturity, and underutilization of these functions. Because the child's oral-motor muscles were weak, the child probably had some frightening early experience with chewing and swallowing. His subsequent avoidance of these activities led to a failure to exercise and strengthen essential oral-muscle tone. The team (including the parents) were in consensus regarding the validity of this evaluation. Together, they developed an intervention plan that identified the behaviors to be shaped, reinforced, or extinguished, and all agreed to make efforts to strengthen oral-motor functioning. In class, the child was offered snacks with the group and given positive attention initially when he accepted a snack on his plate, later when he handled it, and later still when he put it in his mouth to lick the salt. Because he enjoyed salty snacks, these were always incorporated into snack offerings. Attention was a powerful reinforcer, and this was utilized for shaping desired behaviors. Initially, he spat out 98% of mouthed foods. Over time, he began to increase the percentage of food that he swallowed. At lunch time, his parents reported that although he really enjoyed the baby food fruits, he

disliked the pasta and meat most of the time. It was initially agreed to entice him by offering preferred foods. With time, the child did expand his food intake and assume more control over his choices and eating patterns.

The teacher used his high interest in letters and puzzles to incorporate these into his learning times which focused on food puzzles and story books. The speech therapist introduced food activities in the language circle, "Barney eat; Barney chew," and doll care and feeding activities. The occupational therapist used food-related games to teach functional hand skills (picking up small objects, french fries, pretzels) to strengthen self-feeding abilities. All of these activities were repeated frequently and generalized in the classroom.

As the school staff worked with the child, the social worker continued to meet with his parents. Both parents were very concerned and very loving and very much wanted their child to *eat*. But, it was difficult for them to change patterns, especially since the new plan did not lead to immediate and observable changes at home. In order for these parents to move on, they needed to remain mindful of their child's current strengths and capabilities and the advantage in promoting more age-appropriate behavior.

The child's mother, a health care professional who works in a hospital, was herself hospitalized at 33 weeks of pregnancy for toxemia and severe anemia. She was sick and quite weak for the first 3 months after the child's birth. The infant was born prematurely with low birth weight and an early history of initial sucking problems. His status significantly challenged the ability of highly competent parents. We met these parents at school when their child was already 3 years of age, and his habits were established. The mother was still reacting to the birth trauma, her illness, and her child's status: "He was so small he fit into the palm of my hand." She could not shake the image of her baby's fragility and could not envision the child transitioning from a vulnerable infant to a preschooler who could and should eat solid foods. The parents' behavior continued to reinforce infantile feeding and eating patterns. It was necessary for them to develop the hope that a program could offer some success in their wished-for goal in order for them to consider a change in their approach. Opportunities for the parents to observe the occupational therapist and teacher during mealtime as they modeled successful interventions were valuable. And, equally important was the attention of the team to all the parents' efforts to support the school work. Recognition of their efforts promoted the parents' sense of themselves as competent and served to underline their role in helping with the child's growth and abilities in other areas.

In this situation, the mother, as a working parent, wanted the time she did spend with her child to be positive. She enjoyed indulging her baby. She gave him a bottle and did not encourage self-feeding. The situation was further complicated by the fact that while the mother worked, her mother was the primary caretaker. She, too, indulged this poor baby, but also

force-fed him. The team suggested that the child sit at a table for meals (rather than remain propped on a sofa with pillows) and begin to feed himself. The family heard intellectually but initially found this very hard to implement. The mother and grandmother, who were very neat, were distressed by the mess created with self-feeding.

The social worker met frequently with the mother and grandmother and reached out to involve the father. Dad's more optimistic perspective, his readiness to take a risk, and ability to tolerate the mess of self-feeding led to changes. Dad took some vacation time from a busy work schedule so that he could be at home to actively participate in the plan and serve as the model. The child was happy to sit in his own chair at a table that Dad secured. New foods were introduced, starting always with foods the child liked and then moving to table foods more usual with children this age.

Sometimes, the family needed help resolving some of the intergenerational issues that emerged as the father exerted his role in the home. But, as the father became successful, and both mother and grandmother saw changes, they were also able to assume the tasks that promoted the child's progress. The father continued to observe at school and initiate changes at home. It is important to note that one parent may elect to take a lead role in initiating a plan. It is very helpful if this is an agreed-on and explicit plan. Then, staff can offer support.

As time progressed, the players in school and home, working in concert, moved this child from a liquid (bottle) diet to semisolids and solids. Gradually, he began to spit out less and to increase the amount of food he swallowed. Once he began to actually taste the food, he seemed to enjoy it and subsequently (over many months) began to swallow 100% of his food. Although his diet remained limited, it was expanded. Ultimately, he ate chicken cutlets, bagels, french fries, pasta, chips, pretzels, and a few other foods, and drank from a cup.

Over the course of months, some team members became impatient with the parents. It was the family worker's responsibility to help team members maintain their empathic response to the parental struggle. The team leader reinforced this perspective, recognizing that in order to do this very important work they needed to be, according to Dunst (1995), both child focused and family centered. In the end, the outcome supported the wisdom of the team effort which required all staff to be supported for their efforts.

For early childhood professionals, the wish to rescue and to nurture and their passion to provide good care create pressures on each discipline. But, the plan to get the child to eat had to be considered from a developmental and family perspective. In this instance, the team came to consensus: identified learning strategies and behavior interventions across disciplines, clarity around implementation, and behaviors to be shaped, reinforced or ignored. Everyone was a valued player in achieving this goal.

CORE CONCEPTS AND RECOMMENDATIONS

The basic concerns of parental involvement in their child's educational program has been addressed, discussed, and refocused. Promoting the education and well-being of young autistic children and their families is served well through collaborations and interventions that increase the odds of favorable developmental outcomes. Given the short-term opportunity (for children ages 3–5 and their families) and the long-term risk that accompanies neglect, a serious effort to address the needs of families can help ameliorate the challenge of autism. Table 7.1 (Weinstein et al., 2002) will serve as a guide.

TABLE 7.1
Recurring Themes in Work With Families

Theme	*A. Observable Characteristics*	*B. Observable Changes*
1. From Social Isolation and Loneliness to Social Integration	• Reduction in interactions with family and friends	• Increased interaction with family and friends
	• Expresses feeling that they are the only ones going through this experience	• Networks with other parents
	• Does not share concerns about child with family and friends	• Shares and connects with other family members
	• Does not participate in "regular" activities with child (e.g., playground, story hour, family gatherings)	• Selects appropriate activities for parents and child
	• Expresses feelings of being rejected by others	• Begins to develop community connections and strategies for increased socialization (and inclusion) for family and child
2. From Trauma and Mourning to Acceptance and Adaptation	• Expects child will be ready for typical kindergarten or first grade	• Expresses realistic expectations for child's educational needs
	• Preoccupied with searching for more and more services for child	• Demonstrates an understanding of the level of need and appropriate remediations
	• Blames spouse's family for child's disability	• Stops blaming
	• Focuses only on child's strengths	• Recognizes child's strengths and needs
	• Focuses only on child's disability and behavioral issues	• Demonstrates tolerance for range of feelings toward child, including anger, negative wishes for child, upset about child's impact on family life

(Continued)

TABLE 7.1
(Continued)

Theme	*A. Observable Characteristics*	*B. Observable Changes*
	• Expresses negative feelings about demands child places on family	• Expresses acceptance of their own feelings while better coping with needs of all family members
	• Expresses distress at level of child's needs and demands	• Demonstrates strategies to deal with or diminish their own anger
	• Expresses feeling rejected by unrelated child	• Demonstrates diminished feelings of rejection with increased understanding of meaning of child's behavior
	• Avoids interacting with child	• Increased interaction with child
	• Expresses sadness	• Able to discuss and manage sadness
	• Expresses loss of hope	• Able to discuss and manage loss of hope
	• Beginning to question how child's issues fit with their ideas of family life	• Re-define and re-shape their idea of family; create a new family story
3. From Guilt and Anxiety to Self-Esteem and Parental-Competence	• Expresses feelings of guilt and responsibility for child's disabilities; failure to produce a healthy child	• Explores and sorts out feelings of responsibility for child's disability
	• Expresses feelings that if he/she were a better parent, child would not have so many problems	• Demonstrates an increased understanding of the complexity of etiology
	• Judges self harshly (e.g., if he or she had more information on how to help, the child would not have problems)	• Expresses feeling less judgmental of themselves
	• Feels others are judgmental of them	• Expresses feeling less sensitive to others' judgments
	• Places excessive demands on self	• Defines and addresses personal needs and plans for self
	• Demonstrates inability to tolerate pain when discussing child	• Begins to see child as not only a reflection of parents but also separate child with disabilities; can discuss child's functioning
	• Withdraws	• Begins to reestablish social connections

(Continued)

TABLE 7.1
(Continued)

Theme	*A. Observable Characteristics*	*B. Observable Changes*
	• Expresses feeling uneasy about turning child over to another caregiver; trusting others	• Promotes child's attachment to others
	• Separates prematurely from child	• Demonstrates ability to tolerate child's dependence and gradually promotes child's independence
4. From Lack of Understanding to Increased Insight, Knowledge, and Skill	• Does not demonstrate an understanding of the child's disability	• Demonstrates an understanding of the child's needs and strengths
	• Does not know what to expect with respect to child's development	• Demonstrates a greater understanding of child development and realistic expectations
	• Does not know how to deal with child's emotional demands	• Begins to use skills and methods to address child's emotional needs
	• Does not know how to interact with the child	• Demonstrates an understanding of how to better interact with/relate to their child
	• Does not know how to identify priorities	• Begins to identify priorities
	• Does not know how to establish family routines such as bedtime, toileting, mealtime	• Begins to establish family routines
	• Does not know how to plan unscheduled time for child	• Demonstrates ability to use school and community resources to appropriately plan for child
	• Does not know how to help child transition from one activity to another	• Begins to incorporate plans to facilitate transitions for child
	• Demonstrates difficulty attending and managing child at social family events	• Demonstrates ability to plan for child while considering needs of other family members
	• Places excessive demands and expectations on child	• Demonstrates ability to prioritize and select appropriate goals for the child
	• Provides immediate gratification to child to avoid difficult behaviors	• Learns to tolerate and work with child's behavior to promote growth

(Continued)

TABLE 7.1
(Continued)

Theme	*A. Observable Characteristics*	*B. Observable Changes*
	• Expresses significant differences around severity of child's disability	• Increases consensus regarding child's disability
	• Unsure of child's educational needs	• Demonstrates an understanding of child's educational needs
	• Does not understand therapies child receives	• Learns about child's therapies and utilizes observation opportunities
	• Questions child's future educational needs	• Gains perspective on level of need, accessing information, prioritizing, and planning for child's needs
	• Unable to negotiate systems or advocate on behalf of child	• Learns to advocate for child's program and needs
5. From Family Disequilibrium to Family Balance	• Expresses feelings of being overwhelmed with responsibility of decision making (around child)	• Demonstrates ability to identify long-standing conflicts around the child and begins to address and discuss
	• Expresses feelings that child responsibilities are unequally distributed	• Shares childcare and family activity responsibilities
	• Expresses feelings of overwhelming stress	• Demonstrates ability to partialize components of stress and develops strategies for managing and coping
	• Preexisting personal issues interfere with parenting responsibilities or decisions	• Demonstrates ability to identify preexisting personal issues and access services
	• Preexisting marital or couple issues and issues about child interfere with parenting responsibilities or decisions	• Parents select specific areas where they are able to collaborate in service of child
	• Does not discuss concerns and worries about child with partner	• Demonstrates ability to communicate and tolerate different perspectives
	• Limited ability to understand or deal with sibling issues	• Seeks information and resources for siblings; permits siblings to identify and address their own needs
	• Expresses feelings that the child's needs are major focus of family life	• Parents demonstrate ability to balance and plan for all family members
	• Extended family minimizes or is not supportive of parents	• Grandparents or extended family more empathic and involved in child's programs

CONCLUSION

More schools across the country now implement a federal policy that requires children with disabilities to be included in regular education classes wherever possible (IDEA Amendments, 1997). Recognizing parents as valuable and indispensable partners with regard to the education of their children and involving them in decisions regarding the IEP, placement, and the child's progress is now the law of the land. An understanding of the impact the autistic child has on family life and a more open and friendly school system will facilitate a partnership with parents. An increase in parental involvement in their child's education may sometimes be unsettling, but providing them with information and services that recognize their central influence on the child's development is of value to both the school and the child. Despite the challenges parental participation may pose to educators, their input is a reality of life and a legal option with many potential benefits. Together, the school and home may help many more children and families have more satisfying and productive lives.

Blatt (1978) said:

> There have hardly ever been partnerships between parents and professionals, and although the professionals are not entirely at fault, you know as well as I do that we could have done more to make those relationships better. Who can say why we didn't try harder to make it work? . . . I think that close to main reasons is (sic) the idea we have that professionals and parents are too different to develop genuine collaborations, that we know so much and they know so little, that we are ever so much better. I think that many professionals have the idea that we can't possibly have the clients' nasty problems. The disease of professionals is that we believe we are too good for the illnesses and problems with which we are required to deal. The disease of consumers is that they believe us, that they refuse to remember that people are people, that all are in need of something and someone. (p. 6)

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Part III

EDUCATIONAL PROGRAMMING, INTERVENTION, AND MEDICAL TREATMENT FOR PERSONS WITH AUTISM

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Chapter 8

Assessment of Children With Autism

Jan S. Handleman
Lara M. Delmolino
Douglass Developmental Disabilities Center
Rutgers, the State University of New Jersey

INTRODUCTION

The complex characteristics of students with autism pose a challenge to the process of comprehensive assessment. Diverse school, home, and community needs dictate an individualized and comprehensive assessment process to ensure appropriate treatment planning. Successful and productive assessment practices require input and participation by both professionals and family members. Discussions of assessment practices with students with autism typically include a focus on both traditional testing practices and behavioral assessment. Whereas the merits and weaknesses of each approach have been argued, current strategies tend to reflect a blending of these two components. This combined approach produces information about a student's relative standing and individual performance. The ultimate focus of assessment on planning and programming makes this process more compatible with the specialized needs of individuals on the autism spectrum.

This chapter focuses on these and other issues pertaining to the comprehensive psychological, educational, and behavioral assessment of students with autism. Various components of systematic assessment are presented, along with a discussion of the complementary roles of traditional and behavioral assessment. In addition, descriptions are included of the many available instruments and models of assessment.

PURPOSE AND GOALS OF ASSESSMENT

One of the fundamental goals in conducting an evaluation of students with autism is to gain general information about an individual learner and understand the ways in which the disability impacts the individual's behavioral and learning profile. Comprehensive assessment practices can assist in the initial identification of specific areas of learning difficulty. Further, confirmation of a discrepancy between a student's current functioning and expected performance can then guide additional diagnostic assessment to uncover particular deficits. Thus, standardized tests, combined with clinical observation and informal measures, can facilitate the evaluation of various areas of performance and can result in an index of general ability and achievement. This process emphasizes traditional variables of learning, as well as consideration for issues such as instructional control, generalization, and maintenance.

In addition to identifying or confirming the presence of a general disability or learning difficulty, the assessment process serves the fundamental purpose of identifying both strengths and weaknesses of an individual child (Simpson & Zionts, 2000). The process of generating a skill profile for a student is a prerequisite to formulating an appropriate treatment plan. A thorough assessment not only gathers general strengths and weaknesses across skill domains but also identifies other learning variables that may be related to performance across domains.

Further, the use of standardized instruments and developmental measures allows for comparison of the target individual to peers. Peer comparison groups include typically developing individuals of the same chronological age as well as developmentally delayed peers of the same age. Additionally, the use of standard scores and age-equivalent measures allows for the comparison of children with disabilities to nondisabled peers of the same developmental level and provides objective data to track developmental growth.

Although this comparative use of assessment is often secondary to obtaining individualized data pertaining to a specific student, such peer comparison does have an appropriate place. These comparisons may be utilized to further identify magnitude of relative strengths and weaknesses. These comparisons may provide essential information when considering the amount and type of support that may be required to ensure maximum habilitation and effectiveness in the individual's environment.

Information regarding a learner's relative strengths and weaknesses, learning profile, as well as peer comparison data are important in establishing a global picture of the student. Examination of all these levels of data provide a starting point for treatment priorities and help to organize immediate as well as ultimate goals. Without the use of assessment measures

to guide intervention, starting points may be vague or inappropriate for any given individual.

Following the initiation of intervention based on this preliminary assessment data, treatment progress may be monitored with subsequent use of assessment (Pemberton, 2003). Descriptive and quantifiable data can provide benchmarks and serve as a baseline against which future functioning may be measured. The comprehensiveness of an initial assessment will provide a wide range of baseline measures across multiple domains of functioning. This is essential for parents, educators, and clinicians who are evaluating treatment efficacy. In addition, comprehensive assessment can result in a testing–teaching cycle that will guide the complex developmental and behavioral programming required by the student with autism (Mullen & Frea, 1995).

ISSUES AND CONSIDERATIONS IN AUTISM

Despite the clear utility and need for assessment data at many levels, individuals with autism present a unique and difficult skill and behavioral profile that often poses a challenge to traditional processes of assessment. Careful consideration of the distinctive characteristics of the disorder is essential to understanding and overcoming common obstacles in assessment. These characteristics and common assessment hurdles are described in the following sections, followed by potential strategies to offset these challenges.

Testability

Psychological and educational assessment of children with autism has long been recognized as challenging and complex endeavor (Rutter, 1985). Historically, the majority of children with autism have been considered "untestable" by standardized means (Klin, Carter, & Sparrow, 1997). It was previously believed by many that the challenges posed by some children with autism in testing situations were a result of "noncompliance" or "negativism," although research has demonstrated that specific cognitive limitations are more likely the cause (Klin et al.).

For those children with autism who demonstrate difficulties in establishing and maintaining attention, who often lack motivation to participate in assessment activities, and who demonstrate disruptive behavior, attempts at evaluation may assess "test taking ability," without offering any useful information about their intellectual ability or skills (Koegel, Koegel, & Smith, 1997). Overcoming this obstacle of engagement is vital for obtaining both valid and useful assessment data.

Another issue related to testability of children with autism is the validity and availability of appropriate instruments for assessment. In the past, it has been suggested that the use of many standardized tests with individuals with a developmental level below 36 months is generally invalid (Lord & Schopler, 1989). Other current opinion suggests that any use of standardized assessment of children with autism is inappropriate due to the characteristics of autism and the nature of standardized instruments (e.g., Koegel et al., 1997; Magiati & Howlin, 2001).

Idiosyncratic and Uneven Performance

Despite cognitive or academic strengths in a number of students with autism, many of these students lack self-help and other adaptive skills at a level consistent with their cognitive abilities. The uneven developmental profiles that result contribute to the intricacies of assessment. Often, the presence of splinter skills in narrow ranges of functioning may generate misconceptions about the general ability and overall development of individuals with autism (Klin et al., 1997). For example, a young child may demonstrate an advanced knowledge of letters or numbers, or demonstrate emerging reading ability while exhibiting significant difficulty with basic imitation or receptive language tasks. Thorough and comprehensive assessment is a critical part of obtaining and organizing the necessary information regarding an individual child's strengths and weaknesses across multiple domains.

Wide discrepancies in skill across areas of functioning also complicate the issue of test selection (Taylor, 2000). Individual instruments may not provide a wide enough range to account for minimal or emerging abilities in some domains while capturing dramatic strengths in other areas.

Most students with autism demonstrate developmental delays or discontinuity, and often, as they grow older, the discrepancy between chronological age and developmental level tends to increase. Because of this, standard scores on assessment instruments may show a downward trend over time, due to the fact that individuals with autism may not be achieving developmental gains that are consistent with increases in their chronological age (Delmolino, Harris, Jennett, & Martins, in press). This pattern of development may make assessment comparisons over time more challenging.

Behavioral Characteristics That Impede Assessment

A number of diagnostic features and behavioral characteristics of children with autistic disorder present significant challenges to evaluators. Although specific behavioral challenges may not be universal across the population,

the nature of communication deficits, social impairment, and stereotyped interests and repetitive behavior are endemic and manifest in a variety of ways.

Language and Communication Impairment

Current research suggests that 35% to 40% of individual's with autism fail to develop functional speech (Mesibov, Adams, & Klinger, 1997), despite findings that the physiological and structural components for speech are intact (Charlop-Christy, Schreibman, Pierce, & Kurtz, 1998). Earlier estimates placed the figure at nearly 50% of children demonstrating a total lack of functional speech (Rutter, 1978). Although research suggests that a greater proportion of individuals with autism are developing functional speech than was true several decades ago, a great many of those individuals continue to present with significant delays and abnormalities in language development.

For students entirely lacking speech, assessment challenges are clearly evident. Assessment that requires verbal responding is often not feasible with this population. Indeed, lack of expressive language often continues to preclude the valid use of many standardized assessments as documented in the original work by Lord and Schopler (1989). In addition, even when individuals demonstrate the ability to respond with language, it is difficult to ascertain when language difficulties further limit responding despite the presence of other cognitive abilities.

Although the impact of expressive language deficits on standardized assessment may be more obvious, receptive language abilities are critical to consider in the assessment process. The ability of the child to comprehend task instructions in order to respond is necessary to achieve a valid assessment of abilities.

In other populations for whom language is impaired, use of nonverbal communication, including gestures and augmentative technologies, may be helpful to convey test expectations and administer items. Individuals with autism, however, demonstrate a range of deficits in the use and interpretation of nonverbal communicative behaviors such as eye contact, pointing, gesturing, and use of facial expression (*DSM-IV-TR*; APA, 2000). This limitation further increases the testing challenge. For additional discussion of nonverbal communication in the discussion of social impairment, see the following sections.

In individuals with autism who develop functional language, certain abnormal speech characteristics are common (Wilkinson, 1998). Children with autism may display both immediate and delayed echolalia, which is the repetition of words or phrases spoken by others. Further, they might demonstrate pronomial reversal, word-order reversals, the use of neologisms

(made-up words), or idiosyncratic language (Wilkinson). Each of these elements related to the development of communication increases the complexity of the assessment process.

Social Impairment

Deficits in interpersonal and social development are pervasive in students with autism and often compound their difficulties with communication (Travis & Sigman, 1998). Children with autism display impairment in the use of nonverbal behaviors during social interaction, such as eye contact, facial expressions, body postures, and gestures (*DSM-IV-TR*, 2000). Further, many children with autism tend to show limited interest in children and adults with whom they are not familiar. These social deficits can be obstacles to establishing effective rapport within an assessment setting and are compounded by the communication challenges present in this population.

Children with autism fail to demonstrate a range of joint attention behaviors (Grossman, Carter, & Volkmar, 1997). In both initiating and responding to joint attention, typically developing individuals use social–communicative skills to regulate another person's experience with an object or an event. Behaviors used in this context are noticeably absent in a number of individuals with autism. Moreover, when behaviors such as pointing, use of gaze, and verbalizations or vocalization are utilized, they are often poorly integrated with each other in the social context (Stone, Ousley, Yoder, Hogan, & Hepburn, 1997).

Difficulties in establishing and responding to joint attention are of paramount importance in an assessment situation. The clinician is faced with the challenge of establishing the child's interest and orienting the child's attention to a particular task or set of materials, when both verbal communication and nonverbal communication are impaired in this regard. Because of this, it may be of particular challenge to generate attention or interest in the task activities.

Deficits in the development of imitative behaviors are also generally impaired across the population (*DSM-IV-TR*; APA, 2000). The general lack of social interest and reciprocity provide limited opportunities for a child's imitation of those around him or her. Impairment in imitation is also a considerable obstacle in an assessment situation. Helping the child to understand task expectations without reliance on verbal instruction, reliable nonverbal cues, or the use of modeling and imitation can be a complex task.

Lack of social interest and a failure to appreciate the reciprocity of social interaction impede the give-and-take process of assessment. A child with autism may not demonstrate an inherent interest in attending to and responding to an examiner. The child may subsequently demonstrate a lack of motivation to participate in a cooperative way with the examiner and the

required activities. For typically developing children, the establishment of rapport and the motivation inherent in the social situation are more readily achieved.

Restricted Interests/Stereotyped Behavior

Restrictive, repetitive, and ritualistic patterns of behavior are also characteristic of individuals with autism and are an integral part of the diagnosis (*DSM-IV-TR*; APA, 2000). This can include an unusual preoccupation with an object or topic that is abnormal in either intensity or focus.

The specific topography of behavior in this domain varies among individuals. A person with autism may develop an unusual attachment to specific objects while lacking more typical social attachments (Volkmar, Carter, Grossman, & Klin, 1997). Further, individuals may engage in repetitive body movements without apparent purpose, self-injurious behavior, or insist on environmental sameness (Lewis & Bodfish, 1998). Repetitive responding and stimulus overselectivity, as identified in the seminal work of Koegel and Schreibman (1976) and that of Lovaas, Koegel, and Schreibman (1979), may also fall within this category, if these behaviors are conceptualized as perseveration of attention and perception (Lewis & Bodfish). Consequently, the person with autism is often very difficult to engage. This may also be compounded by limited curiosity, a characteristic often observed in individuals with autism and included in standardized diagnostic assessments such as the Autism Diagnostic Interview—Revised (ADI-R; Lord, Rutter, & LeCouteur, 1994).

STRATEGIES TO MAXIMIZE SUCCESSFUL ASSESSMENT

Despite the extent of the challenges described previously, many can be successfully addressed by a skilled evaluator who is familiar with a range of assessment instruments, practices, and the characteristic of individuals with autism. Preparation is critical in setting the stage for a successful assessment.

Initial preparation time will vary from student to student; it is important for examiners to consider a number of factors before attempting direct assessment. A detailed intake or referral record can provide a useful structure for the assessment process. Questions can be answered during preassessment conferences with parents and other professionals, and additional information can be obtained by visits to the student's home or class. These preassessment experiences will better equip examiners to conduct successful assessments.

The parent, teacher, or primary clinician can be a very influential person in the preassessment process, as well as throughout the assessment session or sessions (Handleman, 1999). This individual can provide the examiner with valuable information concerning a number of variables, such as a student's

communication ability, general level of compliance, or idiosyncratic response patterns. Behavioral records and videotapes may be made available to the examiner before the evaluation, and preassessment visits to the setting may provide reassurance for the more fearful student. Other helpful preparations might include teaching a new response or increasing tolerance to novel equipment. Often just having the child's parent or teacher present during the session to help motivate, manage, or simply interpret responses can make the difference between a successful and an unsuccessful effort.

Examiners also need to consider many variables when selecting instruments and planning assessment experiences (Delmolino et al., in press). Instrument variables, such as language in instructions and tasks, timed subtests, social or interactive items, and frequency and number of shifts in tasks are important variables to consider (Klin et al., 1997). Formal and informal activities should be planned with regard to student interests, age, and initial sense of ability; however, developmental level may be a more valuable index for individuals with autism than is chronological age.

Successful assessment of students with autism is typically accomplished by familiar professionals in comfortable surroundings (Delmolino et al., in press). When more traditional or formal evaluation is attempted, there are numerous issues to consider. For example, it is usual to expect some reluctance or hesitancy by the student with novel examiners or with professionals who have ongoing, yet infrequent contact. It is also useful to consider the student's comfort with unfamiliar settings such as hospitals or clinics and unusual assessment procedures, materials, and equipment. Establishing familiarity with an examiner or the testing environment during a visit before the assessment may be an important first step for some learners.

Rapport building is a critical step in the assessment process because student comfort is an important prerequisite to a productive session. The amount of time needed to build a relationship with a student with autism will depend on variables such as age and ability. Initial participation by parents can help to make students more comfortable and can help to identify preferred rewards or interpret responses. This involvement can also serve to reduce the anxiety that many parents bring to the assessment session (Handleman, 1999). Additionally, allowing parents to be present with children may allow for a more optimal sample of behavior or skill for certain children (e.g., Koegel et al., 1997). An important part of establishing rapport may also entail establishing the evaluator or setting as conditioned reinforcers, by pairing the new faces or locations with preferred items and activities and with minimal demands initially. Although such arrangement of the testing environment constitutes an ideal scenario, it is important to recognize that this may not always be feasible.

Administration of standardized tests may have to be modified to accommodate the complex needs of students with autism and their idiosyncratic

response patterns (Delmolino et al., in press). For example, it is important for the examiner to assess the style of stimulus presentation and response format and make adjustments if necessary. Whereas these modifications must be noted, using alternative forms of presentation or accepting different responses, such as signs or gestures, can often provide important information and maximize the utility of results.

Examiner sensitivity to individual learning styles can greatly contribute to the success of assessment sessions. Sitting quietly, maintaining eye contact, and attending to test materials are important test-taking behaviors, and it may be necessary to provide occasional encouragement or initial training in these instructional control areas. In some cases, minor modifications, such as completing the assessment seated on the floor rather than at a desk or table, may produce significantly different results (e.g., Koegel et al., 1997).

If an instrument allows flexible administration, it may be beneficial to intersperse tasks so that interest is maintained and frustration with challenging tasks is minimized. Further, the use of established reinforcers or preferred items and activities may be introduced to engage and motivate children and reward participation in the test-taking process (Klin et al., 1997). Although most standardized testing procedures preclude the use of praise or reinforcement that is specific to task performance, Koegel and colleagues (1997) demonstrated dramatic improvement in test performance when on-task behavior and general responsiveness were reinforced contingently with child-specific consequences.

Careful planning and sensitivity to the structure and pace of assessment sessions will provide optimal results and individualization of testing practices (Delmolino et al., in press). Examiners need to carefully weigh the potential benefit to be gained by incorporating any number of such modifications. All deviations from standardized procedures must be reported to avoid misunderstanding and to increase usefulness to other professionals. These variables should be considered when assessment performance is compared over time, in different settings, with different individuals, and with different instruments. Using combinations of assessment tools with careful documentation of necessary modifications will serve to account for potential discrepancies and be essential to meaningful interpretation.

TYPES OF ASSESSMENT AND INSTRUMENTS

Standardized Assessment

Standardized assessment refers to the use of structured, norm-referenced instruments to measure domains of behavior and functioning. These instruments measure domains, such as IQ or cognitive functioning, adaptive

behavior, developmental level, language, and educational achievement. Data obtained via standardized measures place individuals along a continuum of typical development and provide a basis for comparison to the general population. In addition to providing normative information, standardized assessments are characterized by generally structured administration.

Although there is agreement that the sanctity of the test protocol should be highly regarded, the importance of maintaining standardized procedures needs to be weighed against the need for assessment information for students with autism (Klin et al., 1997). In an attempt to focus on individual strengths and weaknesses, the comparative nature of testing may be deemphasized. In addition, it may also be necessary to control interfering behaviors and employ strategies that promote optimal test-taking behaviors. Modifications may produce important information about students who were traditionally described as "untestable," although clinicians are cautioned to specify when deviations in testing procedure have been employed, so that results can be interpreted accordingly. Specific modifications and instruments that allow for flexible administration are described in this chapter.

Psychological Assessment

The process of psychological assessment typically refers to the use of standardized instruments to assess cognitive ability and general development, along with assessment of adaptive behavior and independent functioning. Examining both cognitive ability and application of skills in adaptive behavior assessment is an important part of this process. Often, this information is additionally combined and contrasted to achievement testing or assessment, in which a student's academic performance and skills are measured against their abilities as indicated by a cognitive or developmental assessment. These sources of information are essential to the development of a comprehensive and appropriate treatment plan.

Cognitive and Developmental Assessment. There is a general need for caution when administering and interpreting the use of standardized measures of IQ with individuals with autism. Indeed, the validity and appropriateness of the use of these measures for children with autism have been questioned by some (e.g., Koegel et al., 1997), due to the social and communication deficits and other behavioral challenges inherent in this population. Other authors (Magiati & Howlin, 2001) suggest utilizing more than one measure of cognitive ability to minimize measurement artifacts, particularly when information about cognitive functioning is included in research.

Measures of IQ that are frequently utilized in the general child population include the *Stanford–Binet Intelligence Scale—Fourth Edition* (Thorndike, Hagen, & Statler, 1986) and the *Stanford–Binet Intelligence Scale—Fifth Edition*

(Roid, 2003); *The Kaufman Assessment Battery for Children* (K-ABC; Kaufman & Kaufman, 1983); The *Wechsler Intelligence Scale for Children* (WISC-III; Wechsler, 1991), and the Wechsler *Preschool and Primary Scale of Intelligence—Revised* (WPPSI-R; Wechsler, 1989); and *The Differential Abilities Scales* (DAS; Elliot, 1990). These instruments have demonstrated adequate validity and reliability in typical populations and can provide information about individuals with autism across a range of skill domains. However, the language demands, use of timed tests, and need for sustained attention on many subtests of these instruments suggest that they may be most appropriate for individuals with autism who do not have significant cognitive impairment (Sattler, 2002).

The *Stanford–Binet Intelligence Scale* (Thorndike et al., 1986) is designed for administration to individuals aged 2½ years to adult. The instrument is comprised of verbal reasoning, abstract and visual reasoning, quantitative reasoning, and short-term memory scales. Information about each of these skill areas and their contribution to a composite IQ score can be obtained. In one study utilizing the *Stanford–Binet* with young children with autism, a pattern emerged with children showing a relative strength in the Pattern Analysis subtest on the abstract and visual reasoning scale, and greater difficulty in the Absurdities subtest on the verbal reasoning scale (Harris, Handleman, & Burton, 1990). Additional research utilizing this instrument may add to the information available to clinicians and educators about the relationship of the included skills to each other and their changes over time for children with autism and individual learners.

Although a newer version of the *Stanford–Binet Intelligence Scales* has been published, the fourth edition is still widely used. Further, a substantial proportion of the landmark research involving IQ and autism intervention utilizes the fourth edition (e.g., Lovaas, 1987; Harris & Handleman, 2000). Because of it's clinical utility and significance in the research, the fourth edition currently remains relevant to the assessment of children with Autism.

In the new version, the *Stanford–Binet Intelligence Scales—Fifth Edition* (Roid, 2003), a number of modifications have been made. The test makes use of both verbal and nonverbal routing tests to determine test starting points and address challenges with individuals who have language difficulty and lower cognitive functioning. The fifth edition assesses five factors: Reasoning, Knowledge, Working Memory, Visual, and Quantitative. Further, verbal and nonverbal scores can be compared for additional analysis (Roid, 2003). Although research utilizing this instrument has not been conducted with individuals with autism, the modifications described here may make it a valuable addition to assessment of children with autism at a variety of age and skill levels.

Similar information is obtained with the Wechsler scales, with the WISC-III (Wechsler, 1991) for children aged 6 years through 16 years, and the WPPSI-R (Wechsler, 1989) for preschoolers, aged 3 years to 7 years. Scales

and subtests on both Wechsler instruments are organized to generate a verbal IQ and a performance IQ, emphasizing visual–perceptual motor reasoning as well as a test composite score. Some research has suggested a pattern of strengths and weaknesses on the Wechsler scales for children with autism, with performance IQ being greater than verbal IQ (e.g., Allen, Lincoln, & Kaufman, 1991), particularly for individuals with a full-scale IQ of less than 85 (Rumsey, 1992). Additionally, there has been some evidence to suggest a tendency for individuals with autism to show lower scores on the Comprehension and Picture Arrangement subtests and higher scores on the Block Design and Digit Span subtests (Rumsey). Additional research, however, did not replicate the consistency of these effects in a sample of high-functioning individuals with autism (Seigel, Minshew, & Goldstein, 1996), and the authors caution against using IQ profile information for diagnostic purposes.

The K-ABC (Kaufman & Kaufman, 1983) is a measure of intelligence for children ages 2½ to 12½ years. The instrument assesses skills in two cognitive domains, sequential processing and simultaneous processing, and provides an achievement scale for assessing acquired knowledge in areas such as reading and arithmetic. It has been suggested that individuals with autism may present with a greater deficit with sequentially processed information compared to spatial tasks, which can be conceptualized as simultaneous processing (Allen et al., 1991). However, findings from preliminary research in this area found no differences on the K-ABC scales in children with autism (Allen et al.) Additional research (Allen et al.) found that children with autism obtained higher scores in the simultaneous processing scale than on the sequential processing scale, although these differences were comparable to a group of children with receptive language disorder when level of language impairment was controlled.

Another instrument, the DAS (Elliott, 1990), is comprised of cognitive and achievement scales for children 2½ to 17 years. The instrument is divided into early-preschool, late-preschool, and school-age sections and has scales reflecting verbal reasoning, nonverbal and spatial reasoning, and nonverbal and fluid reasoning, and yields a general cognitive ability score (GCA). The DAS GCA is reported to have satisfactory concurrent validity with other measures of intelligence (e.g., *Stanford–Binet Intelligent Scale—Fourth Edition* and the *Wechsler Scales*), although it is less highly correlated with other tests of achievement (Elliot, 1990). Although standardization and research have not been conducted utilizing the DAS with children with autism, the instrument may have potential utility due to its wide age range and accompanying achievement assessments.

Other cognitive and developmental instruments are often utilized with children with autism in place of, or in addition to, the previously described IQ measures, particularly when there are concerns about significant cognitive impairment or significant language deficits, including nonverbal

children. These include *The Leiter International Performance Scale—Revised* (Roid & Miller, 1997), *Test of Nonverbal Intelligence—Third Edition* (TONI-3; Brown, Sherbenou, & Johnsen, 1997), *Merrill–Palmer Scale of Intelligence* (Stutsman, 1948), *Bayley Scales of Infant Development* (BSID-II, Bayley, 1993), and *The Psychoeducational Profile—Revised* (Schopler, Reichler, Bashford, Lansing, & Marcus, 1990). Some of these instruments offer more flexible administration, less reliance of language, and assessment of lower basal level skills. These factors are important when assessing children for whom other standardized IQ measures are inappropriate, or offer an incomplete picture of the child's uneven skill profile.

The Leiter-R (Roid & Miller, 1994) is a nonverbal test of fluid intelligence with items covering an age range of 2 years to 20 years. The Leiter-R provides a standardized scale for assessing visualization and reasoning, and additionally offers an attention and memory battery. Moreover, the revision of the Leiter includes growth scores, which may be more sensitive to small changes in ability over time as compared to standard scores (Roid & Miller, 1997). Similarly, the TONI-3 (Brown et al., 1997) is a test of nonverbal intelligence, reasoning, and problem solving in children aged 6 years to adult. Because of the higher floor, use of the TONI-3 may not be appropriate for individuals with more significant levels of global impairment. One study assessing the utility of the TONI-2 in children with autism found that in a sample of 393 individuals, 258 could be assessed with the instrument (Edelson, Schubert, & Edelson, 1998). Analyses indicated that high ratings of difficulty with attention predicted those individuals who could not be tested, although verbal ability was not predictive of testability in this sample. This research lends support to the utility of the TONI in assessing nonverbal children with autism. Despite the advantages of these nonverbal IQ measures for assessing children with autism, a number of authors caution that the estimate of nonverbal IQ may represent a different construct than IQ generated by other standardized measures of IQ such as the *Stanford–Binet* and *Wechsler Scales* (e.g., Shah & Holmes, 1985) or even the performance scales of these instruments (e.g., Lord & Schopler, 1989).

The *Merrill–Palmer Scale of Mental Tests* (Stutsman, 1948) assesses visuospatial abilities from 18 months to 4 years and was originally developed to for administration in place of or in addition to the *Stanford–Binet.* The scale is commonly used in assessing children with autism because of its flexible administration and use of nonverbal items and materials (Lord & Schopler, 1989; Magiati & Howlin, 2001). Despite the strengths of the *Merrill–Palmer Scale* with this population, evaluators are cautioned to consider the instrument's need for updated norms when interpreting scores (Magiati & Howlin). In addition, Magiati and Howlin demonstrated that the *Merrill–Palmer* generally produces higher estimates of IQ than do other instruments and suggest that it may be most useful in combination with

additional assessment information. The higher estimates of IQ based on visuospatial processing is consistent with other research showing relative strengths in the performance and visual reasoning domains of the *Stanford–Binet* or *Wechsler Scales* (e.g., Allen et al., 1991; Harris et al., 1990).

Similar to the *Merrill–Palmer*, the *Bayley Scales of Infant Development* (Bayley, 1993) allow for flexible administration and assessment of skills at a very young level, ages 1 month to 42 months. The *Bayley* provides information about physical and cognitive development, producing mental development and psychomotor development indices (Bayley, 1993). In their research utilizing the *Bayley* in a sample of children with autism, Magiati and Howlin (2001) report that the *Bayley* produced lower estimates of IQ than did the *Merrill–Palmer* when both were utilized. It has been suggested that a significant difference between the two instruments is the emphasis of social development in items on the *Bayley* as compared to the visuospatial skills involved in the *Merrill–Palmer* (Lord & Schopler, 1989; Magiati & Howlin). The use of both instruments in combination provides information about the specific strengths and weaknesses of an individual child.

The PEP-R (Schopler et al., 1990) is a developmental assessment instrument designed for administration with children with autism, ages 6 months to 7 years. Skill areas assessed by the PEP-R include 7 domains of development: imitation, perception, eye–hand integration, fine motor, gross motor, cognitive verbal, and cognitive performance. The test yields scores and age equivalents for each domain as well as an overall developmental score and age equivalent that can be converted to a developmental quotient. The authors highlight several features of the PEP-R that make it uniquely suited for assessment of "uneven and idiosyncratic learning patterns of children with autism" (Schopler et al., p. 3). Items do not need be delivered in any particular order and many items can be presented with little or simplified language if needed. Also, the very young age level allows for assessment across a wide range of skills, which is helpful in situations where children have very uneven skills (Schopler et al.). The authors report that use of the developmental quotient is most similar to IQ measures obtained on the *Leiter* or *Merrill-Palmer* assessments, and can supplement more standardized IQ information (Schopler et al.). Further, the PEP-R contains a behavioral rating scale so that symptoms of autism along four dimensions (relating, materials, sensory, and language) can be observed and recorded.

Although a number of instruments are available to assess cognitive and developmental skills, the diversity among individuals with autism presents a challenge to the process of assessment. Specific assessment tools may be more uniquely suited to particular behavioral characteristics and developmental levels. The use of multiple instruments in combination will help provide the most comprehensive evaluation, and will allow for greater flexibility in comparison and tracking over time. More research is needed utilizing

combinations the instruments described and other measures of cognitive skill across the range and characteristics of cognitive development in individuals with autism.

Adaptive Behavior Assessment. Standardized assessment of adaptive behavior is most often the second component following cognitive assessment in psychological evaluation. Usually, this is conducted via interview-based instruments. *The Adaptive Behavior Scale-Second Edition* (ABS-2; Lambert, Nihira, & Leland, 1993), The *Vineland Adaptive Behavior Scales* (VABS; Sparrow, Balla, & Cicchetti, 1984), and the *Scales of Independent Behavior—Revised* (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996) are three widely used instruments for assessment of adaptive behavior across a number of special populations, though none of these instruments is specific to autism.

The *Adaptive Behavior Scale–Second Edition* (Lambert et al., 1993) is a widely used instrument to assess an individual's level of functioning in school and in the community. Independent functioning is assessed through parent or teacher interview across a number of factors. Part I includes personal self-sufficiency, community self-sufficiency, and personal-social responsibility. Part II of the instrument addresses social adjustment and personal adjustment. Although published research regarding the use of the ABS-2 with individuals with autism is still needed, previous research has explored the use of the original ABS (Nihira, Foster, Shellhaas, & Leland, 1975) with individuals with autism. In the only available study, Sloan and Marcus (1981) found the ABS to be reliable and generally useful in measuring change over time in a sample of individuals with autism, although the authors report that the behavioral ratings in Part II of the scale were difficult to interpret and apply to the population. Additionally, these authors comment on the relatively limited range of items relevant at the preschool level and the need for additional observational data to be included when utilizing the instrument for treatment planning (Sloan & Marcus, 1981). Despite need for additional research, the ABS-2 remains a very widely used adaptive behavior measure with relevance across a number of populations (Harris, Glasberg, & Delmolino, 1996).

The *Vineland Adaptive Behavior Scales* (Sparrow et al., 1984) are frequently used in studies of children and adults with autism. The VABS is administered via interview in one of three forms: the expanded interview, the survey form, and the classroom form. The instrument generates norm-referenced scaled scores as well as age-equivalent scores in four broad development domains: motor, communication, daily living, and socialization. A number of studies have examined the use of the VABS with individuals with autism (e.g., Freeman, Del'Homme, Guthrie, & Zhang, 1999; Harris, Handleman, Belchic, & Glasberg, 1997; Schatz & Hamdan-Allen, 1995). These studies have shown the instrument to be sensitive to changes over time (Freeman

et al.; Harris et al.). Freeman and colleagues demonstrated that improvement in the communication and daily living skills domains was related to initial IQ in their sample of 201 individuals with autism but that changes in socialization were not. Further, it has also been reported that *VABS* scores are often comparable to other standardized measures of performance IQ, such as the *Wechsler Scales* or instruments such as the *Bayley* or the *Merrill–Palmer* (Schatz & Hamdan-Allen). Magiati & Howlin (2001) suggest that the use of the VABS in combination with direct measures of IQ and development and may offset potential over- or underestimation.

The SIB-R (Bruininks et al., 1996) is a comprehensive measure of adaptive functioning across home, school, community, and vocational environments. The instrument is designed for administration in an interview or checklist format, utilizing one of three forms: full scale, short form, or early development. The full scale covers a full range of ages, from infancy to adult. The early development form is designed for individuals from infancy to age 6, or with individuals with severe disabilities functioning below an 8-year level. The short form is designed for screening purposes across all levels. All forms assess an individual's independence across four broad domains: motor skills, social interaction and communication skills, personal living skills, and community living skills, which combine to form the broad independence score. One advantage of the instrument is the flexibility of checklist administration when a caregiver interview is not feasible, and this method has been shown to be reliable (Bruininks et al.). The measure yields standard scores, mastery scores, and estimates of needed support. Research comparing scores obtained with the original version of the SIB to the school edition of the ABS in a sample of children with mental retardation showed high correlations between the two instruments (Bruinicks et al.). However, research regarding the utility of the SIB-R with individuals with autism is still needed.

Behavioral Assessment

A systematic functional analysis of behavior and performance is considered a critical component of comprehensive educational assessment (Durand & Crimmins, 1987; Mullen & Frea, 1995). Appreciation for environmental and physiological factors that impact learning and an understanding of variables that effect student motivation can help to promote thorough educational evaluation and planning.

Behavioral assessment, then, is a process by which the setting and antecedent variables and consequences that affect an individual's performance are examined systematically (Powers, 1997). Behavioral determinants of performance including the physical environment, the temporal sequence of events, as well as socially mediated antecedents and consequences are

examined for individual target behaviors that are identified by the examiner. In this way, the process of behavioral assessment follows a consistent pattern: identification of the target behavior, determination of hypotheses regarding controlling variables, development of a treatment plan, and evaluation of the plan's effectiveness (Powers).

Advantages of Behavioral Assessment

The relationship between behavioral assessment and educational programming is strengthened when the results of evaluation and observation direct planning and programming (Handleman, 1999). A curriculum that emphasizes behavioral excesses, skill deficiencies, and contributing factors will effectively promote individualization. In addition, a teaching methodology that includes sensitivity to individual differences and the importance of variables such as functionality and community application will facilitate optimal performance and progress. This assessment–teaching cycle is further enhanced by ongoing evaluation and performance monitoring. These crucial practices will help to keep the assessment of student needs current and ensure effective goal setting and educational programming.

Ongoing monitoring of performance is one of the most valuable components of the assessment process for students with autism. Criterion-referenced nature of behavioral assessment techniques can typically reflect changing and immediate student needs and promote dynamic educational planning. For example, probes can evaluate learning in all curriculum areas and can help determine if a skill or behavior has been generalized or maintained. Probes can also be repeated to assess the durability or consistency of responding. In addition, charts and graphs can visually present information and provide a permanent record of progress. Each of these techniques provides a valuable tool for ensuring teaching effectiveness and accountability.

Areas of Focus in Behavioral Assessment

Broad examination of behavior is critical to a comprehensive behavioral assessment. Because of the complex behavioral characteristics of students with autism, issues regarding instructional control, generalization, stimulus control, and overselectivity; and input and response modalities may be of special importance in understanding an individual student's learning profile.

Instructional Control. The abilities to focus on the environment, to respond to the multitude of stimuli, and to not engage in competing behaviors are fundamental to skill acquisition by students with autism (Handleman, 1999). Compiling information on a student's ability with these critical instructional control behaviors is an important part of the comprehensive

assessment process. Interpersonal and environmental attending are basic to all areas of learning, as well as to a student's ability to sit and respond to instructional demands.

Generalization Problems and Stimulus Overselectivity. One common concern in assessing and teaching individuals with autism relates to generalization of responses by students with autism (Handleman, 1999). Assessment of the components of generalization, such as setting, teacher, and material, is important in order to complete a student's learning profile. Information about a the use of various types of stimulus and response prompts or the situationally specific nature of responding can be useful in planning assessment strategies and in guiding current and future educational interventions.

Input and Response Modality. Any comprehensive assessment process must be sensitive to individual information-processing styles and to the many possible correlates of learning. After a global screening of the reception and expression of information, a more systematic analysis of learning modalities and motor functioning can be conducted. When the influence of motivational, environmental, and physiological factors are identified and considered in educational planning, appropriate teaching strategies can be more readily implemented.

Functional Assessment

The process of behavioral assessment, when specifically addressing challenging and maladaptive behavior exhibited by many individuals with autism, falls to the realm of functional assessment. Functional assessment procedures are derived from the premise that challenging behavior is operant (i.e., acquired through the principles of learning), and that such behavior is purposeful and often communicative for the individual who is exhibiting the behavior. Substantial research has indicated that challenging behavior is likely maintained by two reinforcement processes: positive reinforcement (access to preferred tangible, social, or self-stimulating consequences) and negative reinforcement (escape from unwanted social, environmental, or sensory stimuli; Carr & Durand, 1985). Elucidation of these variables is a critical component of behavioral assessment, which may indicate clear priorities for intervention.

Functional assessment is a strategy of gathering information regarding an individual's challenging behavior within the context of his or her environment (O'Neill et al., 1997). The process is designed to identify functional relationships between specific behavior and the antecedent and consequent environmental variables that are associated with the behavior for a given individual in a given setting. Comprehensive functional assessment is an essential component of developing effective support plans and is required

by law. O'Neill and colleagues identify five goals of the functional assessment process: description of the target behavior, isolation of variables that can predict the presence or absence of the target behavior, hypotheses regarding the consequences that maintain the target behavior, generation of summary statements, and data to support these.

Information for a functional assessment may be gathered via interview, direct observation, and through systematic manipulations, with a comprehensive assessment often consisting of all three components (O'Neill et al., 1997). There are a number of instruments and tools available to clinicians and educators engaging in the process of functional assessment. The *Motivation Assessment Scale* (MAS; Durand & Crimmins, 1988), the *Functional Assessment Screening Tool* (FAST; Iwata & DeLeon, 1995), the *Functional Assessment Interview* (FAI), and the *Functional Assessment Observation Form* (O'Neil et al.) are a few that are widely available and that have been utilized with individuals with autism.

The *Motivation Assessment Scale* (Durand & Crimmins, 1988) is a questionnaire instrument intended to identify the primary maintaining variables for a specific behavior, and was one of the first of its kind to explore behavior relative to its function rather than to form or topography of behavior. In the MAS, behavioral motivation is categorized along four primary dimensions: attention, escape, tangible items, and self-stimulation. This instrument is straightforward and easy to apply in a number of settings, can be useful in forming hypotheses about the function of behavior, and can promote the development of strategies to address the functions of interest (Durand & Crimmins). Early investigations of the instrument's validity found MAS results to be consistent with results obtained through experimental manipulation (Durand & Crimmins). Some more recent research by Duker and Sigafoos (1998) has suggested, however, that a clinician's bias may affect the outcome, and also that the instrument's reliability and construct validity may depend on the frequency and topography of individual behaviors.

The *Functional Assessment Screening Tool* (Iwata & DeLeon, 1995) is an instrument similar to the MAS, designed to facilitate the analysis of a particular behavior and relevant variables. It consists of 27 statements regarding the behavior of interest, and variables related to potential maintaining variables. The FAST explores social reinforcement (attention, access to activities, and escape) as well as automatic reinforcement (sensory stimulation and pain attenuation). Although ease of use and efficiency are important advantages to using the FAST and other interview or informant measures, it is often recommended to combine their use with other direct observation methods to control for inaccuracies or biases in the reports of informants (Miltenberger, 1998).

The *Functional Assessment Interview* (O'Neill et al., 1997) is designed to be administered to parents, teachers, caregivers, and relevant significant others regarding the individual and behaviors of concern. Additionally, the FAI may

be administered directly with the focus individual. Information is obtained regarding setting variables, efficiency, antecedents, and consequences relevant for specific behaviors of interest. General student information, such as other communicative abilities, access to reinforcing events, and stimulation and history of the behavior are explored. From the information gathered in the interview, summary and hypothesis statements are generated, which guide direct observation, through the use of the FAO (O'Neill et al.). Analysis of observational data serves to confirm or modify proposed summary statements.

Collection of A–B–C (antecedent–behavior–consequence) data is a primary method for gathering observational and descriptive information about behavior and its influencing variables (Miltenberger, 1998). These data may be collected with the use of a standard form such as the FAO, or through standard and less formalized methods. Organization of the range of events preceding and following challenging behavior may help to highlight trends in the data. Closer examination of these behavior patterns is important to the development of hypotheses regarding the function of particular behaviors.

Functional Analysis. *Functional analysis* is a term related to functional assessment that generally refers to the use of systematic experimental manipulations in identifying the controlling variables for a given behavior (O'Neill et al., 1997). In the process of functional analysis, environmental variables are controlled and systematically manipulated, whereas the behavior of interest is observed in order to assess change and demonstrate functional relationships. Rigorous functional analyses often generate data that can further support hypotheses generated in the descriptive assessment phase and serve as an important component to establishing maximally effective treatment plans. Various methodologies for functional analysis are described in the literature and therefore will not be addressed here (e.g., Carr & Durand, 1985; Iwata, Dorsey, Slifer, Bauman & Richman, 1994; O'Neill et al.).

IMPLICATIONS OF ASSESSMENT

Careful analysis and interpretation of results are hallmarks of comprehensive psychological and behavioral assessment. The consideration of test validity and reliability will either heighten or minimize the findings; and variables, such as motivation or consistency of responding, will affect the ultimate utility of these results. Explicit consideration of all modifications and potentially influential variables is a fundamental part of the assessment process.

It is important for examiners to determine whether benefits will be derived from a formal testing process. The student's ability to understand

directions, difficulty with generalization, and the ability to be taught a specific response mode are all important variables to consider. Despite commitment and preparation by examiners, some students will not be amenable to formal evaluation, and reliance on behavioral observations and on the reports of third-party assessments will be necessary.

In addition to the various issues involved in the actual assessment process, there are a number of broader concerns to consider. For example, the initial response to the complex needs of students with autism resulted in the development of highly specialized facilities, often with limited opportunities for mainstreaming (Handleman, Harris, & Martins, in press). Assessing and implementing strategies for the eventual reentry of these students into the mainstream of the general and educational community have, therefore, become a priority for service providers (Handleman & Harris, 2001).

Planning for these important transitional experiences requires systematic assessment and conscientious programming (Handleman et al., in press). The identification of variables such as staff/student ratio, contingencies, school or community life activities, classroom organization, and physical plant can guide approximating the new environment in order to facilitate generalization and optimal adjustment. Follow-up services that are based on ongoing assessment of student progress and performance can then promote continued success of future transitional experiences.

Over the past 20 years, legal, parental, and professional attention has continued to be focused on extended-year programming for students with autism (e.g., Handleman & Harris, 2001). Assessing a student's need for a 12-month educational program continues to be an important, yet difficult task. Because particular students may regress during vacation periods, skill recovery time is an important variable to consider. Another issue refers to the degree to which different skills are vulnerable in the absence of instruction. Disability severity, specific type of learning difficulty, extent of regression, and availability of support to prevent regression are additional considerations for this important educational decision. Decision making that results from extended school-year and transitional planning ultimately facilitates the provision of the comprehensive educational services required by students with autism.

SUMMARY

Comprehensive assessment of children with autism is not a straightforward process. It requires significant expertise in understanding the behavioral characteristics and learning styles of individuals with autism and an appreciation of unique individual variables. In addition, evaluators need to possess a firm grasp of the range of available assessment tools and recognize the

contributions of both standardized and behavioral assessment. With careful planning and consideration of these factors, parents and professionals will be equipped to assemble valuable information about individual students' skills, needs, and progress over time.

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Chapter 9

Teaching Students With Autism Spectrum Disorders

Dianne Zager
Nancy Shamow
Long Island University

INTRODUCTION

James is a 7-year-old boy with autism and severe mental retardation. He doesn't speak, frequently flaps his hands in front of his face, engages in self-injurious behaviors, and requires constant supervision. Maria also has autism. At 7 years of age, she has demonstrated superior intellectual ability and is working on or above grade level in all academic areas. However, due to deficits in social skills, problems understanding abstract language, and several obsessive and compulsive behaviors, she is experiencing great difficulty interacting with her peers. Whereas James does not use speech to communicate, it seems that Maria speaks incessantly about inappropriate topics.

Both James and Maria have been diagnosed with autism spectrum disorders (ASD). Each of these children is experiencing problems in the area of social interaction. Each exhibits unusual behaviors. They both have difficulty with communication. Because their disabilities are manifested in the social, communication, and behavioral domains, these two children have received similar diagnoses, but they each require vastly different instructional programs.

Over the past several years, autism has increased dramatically, becoming the fastest growing developmental disability category in the United States (Autism Society of America, 2003). As the diagnostic criteria have broadened

to include individuals with disabilities that, in the past, would have been classified differently (e.g., learning disability, emotional disorder, mental retardation), the field of autism has expanded. In the previous edition of *Autism: Identification, Education, and Treatment*, this chapter focused on teaching students with moderate and severe classic autism symptoms, as described in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (APA, 1994). For this edition, we continue to include information pertaining to instructional practices for students who have severe autism with cognitive impairment, and we also discuss curricular and methodological concerns for teaching children and youth with high-functioning autism (HFA) and Asperger's syndrome (*DSM-IV-TR*; APA, 2000).

This chapter deals specifically with topics related to educational planning and instructional practices. Specifically, issues pertaining to inclusion in general education programs, paraprofessional roles in the classroom, applied behavior analysis, and selected instructional strategies are presented. Only documented effective practices for the education of students with ASD are included. Although new approaches with unfounded claims are commonly popularized in the special education media, readers may be assured that methods suggested in this chapter have data that attest to their effectiveness.

Because individuals with ASD differ dramatically, and because children may function at varying levels during different developmental stages, this chapter includes information pertaining to instructional practices for students from primary grades through secondary school, and across the entire autism spectrum. This is a tall order and one that, perhaps, would be most easily accomplished through two distinct chapters. However, in keeping with prevailing inclusion practices, we discuss instructional practices based on a broad picture of learner needs and functioning levels, rather than by consideration of cognitive ability alone.

The current body of knowledge can provide guidance and direction for designing instructional programs that are directed toward meeting the unique learning needs associated with autism. Individuals with ASD require specialized instructional programs that take into account their complex and intense learning characteristics, which significantly impact school performance and skill acquisition. These children may exhibit severe language deficits, uneven skill development, extreme behavior problems, and other disabilities in learning and relating to people. Researchers continue to gather new information pertaining to the characteristics and needs of students with autism as they progress through the educational process, from birth to adulthood (see, e.g., Wetherby & Prizant, 2000).

Suggestions are provided in the present chapter to guide teachers, psychologists, speech and language therapists, and other service providers in the development and implementation of basic curriculum and instructional programs. Highly structured instructional programming is necessary

in order to increase the likelihood that students with ASD acquire the skills they will need to lead productive lives within their community. Teachers and other service providers must direct their energies toward this most crucial outcome of independent and supported community integration and utilize strategies and techniques that research has documented to be effective in teaching basic functional skills, academics, and social interaction.

A word of caution pertaining to the adoption of any instructional strategy is in order here. Teachers and parents are often confronted with spectacular success stories about particular programs as they pursue avenues to ameliorate the symptoms of this most challenging disorder (for information about how to discern promising practices from false claims, see chap. 14, this volume, "Treatment Approaches for Autism: Evaluating Options and Making Informed Choices"). In order to avoid wasting valuable instructional time, ongoing assessment to monitor the effectiveness of any selected approach must be a mainstay of every program. Remember that curriculum should be based on realistic goals that have been identified through comprehensive and appropriate assessment, and that instructional activities need to be functional, chronologically age-appropriate, and generalizable. When selecting educational goals, it is necessary for educators to consider the following: (a) student's age; (b) ability level; (c) learning style; (d) behavioral and communicative repertoires; (e) school, home, neighborhood, and future living and employment environments; and (f) personal preferences.

The strategies described in this chapter are based on five tenets: (1) Transdisciplinary team collaboration is essential in the delivery of educational programs for students with ASD; (2) intensive continuous early intervention is necessary to develop communication and behavioral repertoires in students with ASD; (3) individuals with autism require frequent opportunities for interaction with nondisabled peers in integrated and inclusive settings in school and society; (4) instruction should be provided to the maximum extent possible in the context of natural environments in which students will ultimately have to function, while ensuring access to sufficient intensive programming; and (5) systematic employment of applied behavior analytic principles facilitates and enhances skill acquisition.

EDUCATIONAL PLACEMENTS AND SCHOOL OPTIONS

All children have the right to receive a free appropriate public school education in the least restrictive environment possible. Because children on the autism spectrum vary greatly in their cognitive, language, and social abilities, educational placement always must be determined on an individual basis. Educational placement options for students on the autism spectrum include, but are not limited to; (a) full-day integrated regular class placement (with supports as needed), (b) regular classroom placement with special

education instruction for part of the school day (provided by a special education teacher either in general education or in a resource room), (c) self-contained special education classroom with mainstreaming into general education classes as appropriate, (d) full-day self-contained special classroom placement in integrated public school settings, and (e) placement in segregated specialized programs (public or private schools) designed to serve students with autism and other disabilities.

The Inclusion Issue

Debate has raged over the past 2 decades about whether to educate students with severe disabilities in general education classrooms alongside their nondisabled peers or to provide intensive instruction in specialized settings. The inclusion debate has garnered staunch proponents in each camp. To speak out against the inclusion of students with ASD in general education is viewed as an act of heresy in many circles. Inclusion of students with disabilities into the mainstream of school is an issue which many respected educators have decided is a closed and shut case, a proven right of all students. In fact, a major benchmark of success for specialized programs has become the number of youngsters that can be graduated into inclusive classrooms, and state and federal initiatives are typically designed to encourage and foster the inclusion of students with disabilities into general education.

The term *inclusion* has been defined as serving students with disabilities in general education classrooms under the instruction of general education teachers (Mastropieri & Scruggs, 2000). Essentially, inclusion involves providing instruction, with support services when needed, in general education classrooms in lieu of placing students with disabilities in special education classrooms with other students who also have learning and/or behavior problems. Articles in contemporary professional journals, (e.g., Wolfe & Hall, 2003) tend to encourage the practice of inclusion with biased statements, implying that practices other than inclusion are detrimental because they cause exclusion from integrated settings and from peers. It is our belief that, although inclusion in the mainstream of school and society is the ultimate goal for individuals with autism, at particular developmental junctures, the pathway to successful inclusion may require intensive services in specialized settings.

Preparation for integrated community living ultimately requires integrated schools. There is widespread recognition that educational integration is overdue (see, e.g., Salend, 2001; Stainback & Stainback, 2000). Students with disabilities have the right to receive their education in their neighborhood public school, in proximity to typically developing peers. This perspective has long been supported in the literature (e.g., Brown et al.,

1979; Sontag, Certo, & Button, 1979). Gaylord-Ross and Holvoet (1985) reported that the integration of students with disabilities had a positive impact on both the quality of services provided to these children and their acceptance by nondisabled peers.

Whereas children with ASD are entitled to the same rights as are other children, certain characteristics of autism sometimes necessitate specialized instructional techniques that preclude placement in traditional regular or special education settings (Mesibov & Shea, 1996). Essential components of effective programs for children with severe autism include full-day, 12-month programming with high instructor-to-student ratios, ongoing training and supervision of staff, and parent training, in both school and home settings. Learning for many children with autism should initially occur in settings where programming is highly structured, individualized, and skill oriented. Classrooms must provide environments in which predictable routines are followed, and where antecedent conditions and consequent events responsible for erratic responding are identified and controlled. Treatment programs are most effective when they focus on maximizing generalization and minimizing off-task time. The importance of designing learning environments that include individualized motivation systems and that establish contingencies to control behavior at home and in the community cannot be overemphasized.

Although inclusion is seen by some (e.g., Wolfe & Hall, 2003) as an inalienable right, a question not of whether but rather of how to provide education in integrated environments, actual observation of students with autism in general education settings often sheds a different light on the situation. There is no question that students who are capable of benefiting academically and socially from placement in regular classes should receive their education alongside their nondisabled peers to the maximum extent possible. In other words, to the extent that general education placement does not impede the development of requisite skills for learning and lifelong success, and that necessary intervention can be provided, students with autism have the right to be taught in inclusive classes.

Zager, Young, and Seemin (2003) studied the experiences of teachers, parents, and young children with HFA in inclusive education settings. Although the study was limited to a small group of children, findings were consistent for all subjects. For the children in the study, inclusion was perceived as beneficial for the development of language and social skills. In addition, nondisabled students in the classrooms were receptive and helpful to the children with autism. Exposure to typically developing peers was seen as beneficial for the children with autism, and the nondisabled children developed a comfort level with children with special needs.

So then, what could be a problem with inclusion? Problems identified by Zager et al. (2003) included missed opportunities for behavior management

due to difficulty in arranging the instructional environment to maximize learning for the child with autism while at the same time meeting the needs of the other children in the classroom. Regular classroom teachers reported a need to instruct the majority of their students with expressive, colorful, and fast-paced language. They found it difficult, and not in the best interest of the majority of students, to limit language when directions were given to the entire class, when new units were introduced, or when something exciting and unexpected occurred. When confronted with excessive language, abstract concepts, or stimulating distractions the children with autism tended to exhibit problematic behaviors that baffled the general education teachers. The general education teachers, on the whole, were not adequately trained in behavioral intervention techniques to deal with maladaptive behaviors and at the same time provide instruction to the other students in their class.

Inclusion can be viewed as a double-edged sword. Integrated environments offer students with autism, and their nondisabled peers, the opportunity to learn and grow together. Appropriate models of language and behavior are available to students with autism in regular classrooms. Positive supportive interactions can lead to enriched school experiences for all involved. On the other hand, a lack of precision in teaching, inability to adequately structure regular classroom environments, massive doses of rapidly delivered abstract language, and uncontrolled ongoing distractions can be counterproductive for students with autism.

In order for inclusion to be effective, it must take into account the skill level, as well as the unique learning and behavior characteristics of the particular student with autism who is to be included in the general education classroom. Time spent modifying general education curriculum may help enable a student with a severe disability to participate to some degree in a regular class. But will the student be taught necessary and relevant skills at an appropriate level of difficulty, and with specialized instructional techniques? Will the student be adequately prepared for life outside of school?

Many students with autism can perform on a high academic level. For these students, issues related to anxiety, isolation, and depression may need to be addressed. The necessary supports to promote learning and self-esteem must be determined and provided to sustain every youngster. Those responsible for educating children with autism need to recognize that enthusiasm for integrated placements does not take precedence over the most important goal of providing an appropriate education (Kellegrew, 1995). School and community integration are, without question, the ultimate goal of education. A major challenge in meeting the promise of inclusion is to provide instruction in an integrated classroom that concomitantly fosters the development of necessary skills at each student's level and promotes generalization of those skills to school, home, and community.

Paraprofessionals in Inclusive Classrooms

In order to include students with autism in general education classrooms, various supports may be needed. One commonly utilized support involves the employment of paraprofessionals, or school system-paid classroom assistants. The impact and influence of paraprofessionals on the learning and development of students with disabilities can be very significant (Wadsworth & Knight, 1996).

Paraprofessionals can help students with disabilities succeed in inclusive classes. However, there are some potential problems with the use of untrained persons participating in the provision of instruction. For instance, role expectations for teachers to become instructional managers of paraprofessionals can create confusion and frustration because this is not an area of study that is typically included in teacher preparation programs. Also, the presence of a paraprofessional can, at times, impede the acquisition of social skills and of social acceptance. Finally, it is all too common to observe a paraprofessional completing work for a student with a disability in order to help the student keep up with other students in the class. This can usually be avoided through staff training, combined with good planning and appropriate use of the paraprofessional's time.

Paraprofessionals are often asked to instruct, assess, and collaborate within the classroom. Although their role has become increasingly that of a facilitator of learning rather than merely a teacher's helper, these staff members may have very limited training. Boomer (1994) noted that in many school districts paraprofessionals tended to be assigned to particular students, usually those who displayed challenging behaviors. Such one-on-one assignments can be helpful in supporting particular students in integrated environments if carried out properly; but care must be taken to avoid overdependency on the *para* and to ensure that the *para*'s presence does not interfere with socialization. Also the paraprofessional should be closely and continuously supervised by a special educator. Paraprofessionals can assist with implementing Individual Education Program (IEP) goals, monitoring progress, supervising and guiding students with tasks, and communicating with parents; but they should not be responsible for designing plans, interpreting data, or providing instruction without direct supervision.

APPLYING BEHAVIORAL PRINCIPLES IN THE INSTRUCTIONAL PROCESS

Children learn many behaviors in their natural environment simply by watching others and imitating what other people do. For the typically

developing child, these behaviors are maintained by natural consequences including social approval, attention, and affection from adults. For children with autism who lack the imitation skills required to begin learning, instruction must focus on learning how to learn. When their learning environment is systematically and precisely structured, learning is possible.

In addition to significant distortions in the development of speech, language, and communication skills, children diagnosed with autism have multiple skill deficits and exhibit extreme deviation from normal development. Good education programs for children with autism focus on teaching a range of basic skills. The most effective programs share a common set of attitudes and a methodology that is solidly based on science (Harris & Handleman, 1994; Maurice, 1993; Maurice, Green, & Luce, 1996). The methodology that has achieved the most effective treatment outcomes for children with autism is applied behavior analysis (Green, 1996; Powers, 1992). This science was developed from research in the experimental analysis of behavior. It is a positively oriented approach that assumes that behavior is learned and can be changed. An underlying assumption of behavior analysis is that behavior is lawfully determined, with the determiners of behavior located in the environment, not in the child. Applied behavior analysis is data based, outcome driven, research validated, and accountable.

In the classroom, teachers employ research-validated intervention procedures to teach new skills or to remediate behavior problems. Examining the relationship between what they do (the teaching procedure) and what the child does (the learning outcome) allows decisions about whether to continue or modify the intervention to be based on empirical findings and predetermined criteria, as opposed to subjective emotions or feelings. Once again, the goal is to create effective teaching strategies that produce positive learning opportunities for the student. The responsibility for effective learning rests with the teacher, rather than with the student.

As the demand for services increases, the number of education programs providing classrooms for children with autism also increases. Parents in search of appropriate placements for their children, as well as school districts and counties responsible for recommending and funding programs, must identify tools that will help evaluate these programs. The most informative evaluation criterion is student outcome. A critical benchmark of an effective program is the use of curriculum that focuses on individualized data-based treatment and education programs. Individualized programs include written response definitions, objective measurement procedures, and replicable teaching procedures that provide final performance specifications and contingencies required for shaping behavior to criterion.

Reinforcers and Contingencies: The Effects of Environment on Behavior

Behavior is controlled not only by its consequences but also by its antecedents (i.e., events that immediately precede behavior). New skills are both shaped and maintained by the effects they have on the environment. The relationship among antecedents, behavior, and consequences can be described in what is called a *three-term contingency*. An adequate explanation of human behavior requires understanding of the control exerted on behavior by both sides of the relation (Skinner, 1953). Although behavioral consequences affect the likelihood that a response will be repeated (Skinner, 1938, 1953), antecedents determine when and where the response will occur. Effective education and treatment programs for children with autism focus on teaching new skills using positive reinforcement procedures.

Behaviors that produce positive or favorable consequences are more likely to be repeated, whereas behaviors that produce unfavorable or aversive outcomes are less likely to be repeated. Consequences that produce increases in behavior are called *reinforcers*. If the consequence of a behavior is the termination of an unpleasant event and the result is an increase in the behavior, the event is a *negative reinforcer*, and the contingent termination of the event is called *negative reinforcement*. The principles of reinforcement are the same for all human behavior.

Items or events may have different reinforcing value for different people depending on their individual learning histories, needs, wants, and abilities. Whether we call events reinforcers depends on the effects they will have on behavior. An event can only be considered a positive reinforcer if it increases the frequency of the behavior that it follows. Positive consequences that typically interest normally developing children may not be reinforcing to a child with autism. Children with autism respond to a very limited range of reinforcers. They may not respond to verbal praise and may not want to be picked up or like to be touched. If they show interest in a toy, they may not play with it appropriately. They may even generate their own reinforcers that compete with the positive consequences controlled by a teacher or parent.

How Can a Teacher Change Behavior?

To teach a wide range of skills, effective programs must focus on developing a repertoire of reinforcers for their students and a system for clearly specifying the conditions under which these reinforcers are selected and delivered. Observation of a child's behavior provides important clues as to the effect of these consequences. Providing access to a wide array of items

and observing which items the child likes and dislikes can help generate a menu of potential reinforcers. This does not, however, guarantee that the chosen item will function as a reinforcer. The best test of a potential reinforcer is to empirically determine the effect it has on behavior during teaching trials.

Most human behavior is maintained by reinforcers called *generalized conditioned reinforcers.* Examples of these include attention, affection, approval, and tokens, such as points, stickers, and money. Although money has no value to an infant, as a person accumulates experiences in which money is exchanged for items having positive value, it acquires reinforcing value of its own. Food is reinforcing when we are hungry, and a soft drink is reinforcing when we are thirsty. Unlike food and drink, generalized conditioned reinforcers are not dependent on a single deprivation state. They acquire reinforcing value by being paired with known reinforcers.

Positive attention from others and social praise may not function as effective reinforcers for most children with autism. To acquire reinforcing value, praise, smiles, or gestures of affection must be repeatedly paired with the delivery of tangible reinforcers, such as food. By repeatedly pairing praise with strong highly valued reinforcers, positive attention will gradually acquire value and sustain performance. Later, new items and events can become reinforcers by pairing them with these newly acquired secondary reinforcers. In this way, the behavior of children with autism can be brought under the control of the same stimuli that control the behavior of typically developing children.

Skill Building: Developing New Repertoires Through Shaping

Waiting for a desired behavior to occur and then reinforcing it ("catching 'em being good") can produce a variety of new skills. However, if the frequency of the desired behavior is low, it may not always be possible to wait for its occurrence. An alternative to waiting is to differentially reinforce successive approximations to the desired behavior. This gives the teacher opportunities to *shape* the desired behavior from an initial approximation to the final response. The desired response is broken down into small, easy-to-master steps, and a hierarchy is created. If the child is successful in performing the initial step in the hierarchy, the criterion for reinforcement is shifted to an intermediate response and reinforcers for earlier responses in the hierarchy are withheld. Reinforcement of successive approximations is continued until the final response is achieved. The failure to emit a desired behavior may necessitate a return to performance levels defined by a lower step in the hierarchy before continuing.

All too often, children with autism do not comprehend the rules for delivery of reinforcers. They may not understand what behavior is required or when to respond. Teachers must be good contingency managers and clearly specify the conditions necessary for reinforcement. In order to build new behaviors, reinforcers must be *contingent.* Access to reinforcers should only occur if the specified behavior occurs first. Reinforcers must be delivered immediately following the behavior. If reinforcers are delayed and therefore delivered at the wrong time, the effect will be an increase in whatever behavior the child engaged in at the time of reinforcement delivery. Because of the likelihood of inappropriate self-stimulatory behavior in children with autism, the potential for accidental reinforcement of these behaviors is high. For this reason, down-time or free play should be kept to a minimum.

Early in the acquisition of new skills, every correct response, whether independent or prompted, should be reinforced. This rule for reinforcement delivery is called *continuous reinforcement.* Failure to reinforce may produce extinction of the behavior. Although continuous reinforcement is essential during the initial acquisition of new behaviors, care should be taken to avoid satiation effects. When too much of the same thing is delivered, reinforcers lose their value. Saving preferred reinforcers for special teaching times and giving small amounts of the reinforcer can help prevent satiation. The menu of items presented as reinforcers should be constantly varied to create and maintain interest. Teaching children to make choices reduces the lost opportunities to reinforce appropriate behavior that occur when a child refuses an item that you have selected. Providing opportunities to make choices can itself become reinforcing.

After a child is consistently responding, reinforcers can be delivered intermittently (i.e., after some, but not every response). Intermittent schedules give stability to behavior by building delays between the onset of responding and the delivery of reinforcers. Children learn to continue to respond, or persist, in the absence of reinforcement. The effect of teaching persistence is to make the behavior more resistant to extinction. Intermittent reinforcement of inappropriate behavior has the same effect. If problem behaviors are intermittently reinforced, they too will persist and become resistant to extinction. Ignoring a severe tantrum and then giving in results in the reinforcement of extended tantrum behavior that may be difficult to eliminate. When we are not aware of how we are affecting behavior we can inadvertently promote persistence of the exact problem we want to eliminate.

Rules for intermittently reinforcing selected responses are based on either a response count or the passage of time (Skinner, 1938). Characteristic, reproducible, and orderly patterns of behavior are maintained by different schedules of reinforcement. Schedules that deliver reinforcers following a fixed number of responses or the passage of a fixed interval of time produce pauses in responding immediately after the reinforcer delivery. It is typically

during these pauses that off-task behaviors, stereotypic behaviors, or both occur. These behaviors become embedded in sequences of reinforced behaviors and thus persist. Schedules that deliver reinforcers following variable intervals of time or following variable numbers of responses do not produce the same pauses that fixed schedules do. They are more likely to prevent, rather than encourage, the intrusions of stereotopies into otherwise appropriate behavior.

Programmatic Differences in Approaches

Although the past decade has seen increased interest in the use of science based treatment, controversy within the behavior analytic community stems from the recent introduction of alternate behavioral approaches (e.g., precision teaching, applied verbal behavior, natural environment teaching) along with methodological differences in the way skills are taught. Disagreements among proponents of different approaches center on variations in curriculum content, the setting where skills are taught (artificial or natural environment), the allowance of errors, and the criterion measure (accuracy or fluency).

Skinner's seminal book, *The Behavior of Organisms* (1938), described 10 years of research in which he identified the relationship between operant behavior and its controlling variables. Skinner's *Verbal Behavior* (1957) extended this scientific analysis to explain language acquisition, whereas his *The Technology of Teaching* (1968) extended his analysis to the field of education. His work serves as the cornerstone of all behavior analytic procedures. The behavioral literature of the 1950s and 1960s contained numerous examples of laboratory and clinical demonstrations extending the principles of behavior derived from animal research to human subjects.

Pioneers, such as Ogden Lindsley, a student of Skinner, applied these methods to teach psychotic children and adults. Lindsley's use of Skinner's *free operant* conditioning technology to train special education teachers in public school classrooms led to the development in 1965 of precision teaching (Lindsley, 1990). This fluency-based, criterion-referenced instruction affords students opportunities to respond at their own pace without restraints placed on them by the limits of the materials or the instructional procedures of the teachers (Lindsley; West & Young, 1992). New behaviors are taught to a level of fluency that can be generalized and be maintained in natural environments.

In the 1970s, O. Ivar Lovaas applied behavioral principles to teach language, play, social interactions, and self-help skills to institutionalized children diagnosed with autism. Lovaas' work at UCLA led to the development of discrete trial teaching (DTT) (Lovaas, 1987). Unlike the free-operant

format of precision teaching, in which students practice skills at their own pace, DTT is teacher-directed. The teacher determines the pace of instruction, selects the teaching stimuli, and creates consequences that are easily manipulated and controlled, but often unrelated to the teaching stimuli (McGee, Krantz, & McClannahan, 1985).

Both precision teaching and DTT schedule consequences until the skill is established. Both forms of applied behavior analysis focus on directly observable behaviors that can be measured and analyzed to assess student learning. Both are precise and systematic methods of evaluating instruction. Neither approach prescribes what should be taught or how to teach. Regardless of the behavior analytic approach selected by teachers, the acquisition of new skills depends on the contingent delivery of reinforcers following desired behavior. These are not competitive strategies but different applications of the same basic science.

Discrete Trial Teaching and Incidental Teaching: Two Learning Formats of Applied Behavior Analysis

Compared to traditional classroom instruction, DTT teaching provides students with multiple opportunities to practice skills. The classroom teacher typically sits face to face with one or more students in a setting that minimizes distractions. Teaching interactions begin with the presentation of a teaching stimulus (a direction or question). Correct responses are followed by the delivery of reinforcers. Errors (failure to respond or incorrect responses) are corrected and followed by the next teaching interaction. Each teaching sequence is identical to the previous one and contains a clear beginning and end. Data are pooled across teaching trials to evaluate student outcomes.

DTT procedures differ in the extent they allow errors to occur. Contrary to popular belief, students do not learn from their mistakes. The occurrence of errors reduces the overall frequency of reinforcement, decreases the time available for instruction, and may produce inappropriate emotional responses, including disruptive, self-injurious, or aggressive behavior (Carr & Durand, 1985; Martin & Pear, 1999). Effective instruction creates opportunities for children to succeed without making errors (Corey & Shamow, 1972; Moore & Goldiamond, 1964; Terrace, 1963a, 1963b). To establish control of newly acquired behaviors, it is sometimes necessary to help a child attain a reinforcer by prompting the desired response. A prompt is an additional stimulus (vocal, visual, gestural, or physical) that increases the likelihood that a discriminative stimulus will occasion the desired response. Prompts should be related to the task and should be removed as soon as the need for them no longer exists. Inadvertent, excessive, and repeated prompts should be avoided or a dependency on the prompt develops. When teaching

independent tasks, care should be taken to avoid embedding prompts into the teaching procedures. Physically prompting a child through all or part of a response and then reducing manual guidance permits the *errorless* acquisition of a response by naturally occurring stimuli in the environment (MacDuff, Krantz, & McClannahan, 1993).

Errorless script fading procedures have also been used to promote verbal initiations in preschool and school-age children with autism (Krantz & McClannahan, 1993, 1998; Sarokoff, Taylor, & Poulson, 2001). Conversational language of children diagnosed with autism has been increased using a variety of procedures, including the Picture Exchange Communication System (PECS; Charlop-Christy, Carpenter, Le, LeBlanc, & Kellet, 2002), modeling and verbal prompting (Gena, Krantz, McClannahan, & Poulson, 1996; Williams, Donley, & Keller, 2000), written prompts (Krantz & McClannahan; Matson, Sevin, Fridley, & Love, 1990; Sarokoff et al.; Thiemann & Goldstein, 2001), time-delay procedures (Matson, Sevin, Box, & Francis, 1993; Taylor & Harris, 1995), video modeling (Charlop & Milstein, 1989), pivotal response training (Koegel & Frea, 1993), and a tactile prompting device (Shabani et al., 2002: Taylor & Levin, 1998).

Although DTT is effective in teaching children to respond correctly, critics argue that DTT creates an artificial learning environment where teachers direct trials while students learn to wait for instruction. The argument is that children taught this way do not learn to self-initiate or respond to natural cues and consequences (Hart & Risley, 1968). To become functional and spontaneous, any skill that is taught in isolation must become integrated into the context of the child's day. Children must attend to appropriate environmental stimuli, generalize these skills and use them spontaneously. To foster acquisition and the generalization of newly learned behaviors, teachers must bring these skills under the control of more natural contingencies (Baer, Wolf, & Risley, 1977).

Incidental teaching procedures in which children initiate teaching episodes in the context of everyday situations and naturally occurring stimuli result in both spontaneous emission of functional language and enhanced generalization (Hart & Risley, 1968; McGee, Krantz, & McClannahan, 1985, 1986). By changing the learning environment to promote incidental learning, skills acquired in a discrete trial format may be generalized and maintained by natural rather than by arbitrary consequences. Placing high-interest toys and activities out of reach brings verbal behavior under the discriminative control of nonverbal referents in the environment (establishing operations) rather than the behavior ("What do you want?" or "What is it?") of others. Ultimately, a child must learn to ask for objects that are not present, answer questions when asked about identifiable stimuli, or talk about objects or events that are not visible to the listener.

Skinner's (1957) analysis of verbal behavior provides teachers with a conceptual framework in which intervention strategies can be developed to

teach communication skills to children with autism under the same environmental contexts that language is used (i.e., the natural environment). Within this framework, words (whether spoken, written, or signed) influence others to act on what we say. Verbal behavior is reinforced and maintained by the control it has on the behavior of the listener. Skinner identified basic functional units of language (echoic, mand, tact, and intraverbal) and the environmental variables (discriminative stimuli, establishing operations and consequences) responsible for their acquisition. The acquisition of spontaneous speech requires a strong vocal imitation repertoire in which the child's verbal response echoes with point-to-point correspondence someone else's verbal behavior. Once a child has a strong echoic repertoire one can teach across all functions of language by prompting and reinforcing echoic responses. *Mands* (requests) are reinforced by the consequences they produce. They serve to obtain access to the things children want, such as objects ("Can I have that?"), attention ("Look what I did."), or information ("What time is it?").

The reinforcement value of consequences is determined by the level of deprivation or aversion (establishing operation). Mands are taught under high levels of deprivation. Children learn to tact, or label things that are found in the nonverbal environment such as nouns for objects, verbs for action, prepositions for relations, and adjectives and adverbs for properties of objects and action under low levels of deprivation. Tacts ("That's a table.") are maintained by secondary reinforcers. Partington and Sundberg's (1998) *The Assessment of Basic Language and Learning Skills* (ABLLS), derived from Skinner's analysis of verbal behavior, is widely used as a curriculum guide for determining what educational objectives to teach and how to teach them.

Beyond Acquisition: Maintenance, Fluency, and Generalization

Children with autism often exhibit a repertoire of inappropriate behaviors that fill the vacuum produced by multiple skill deficits. Within the structure of a DTT session, these behaviors are replaced by trials of motor imitation, direction following, and verbal responses to questions. Outside of the structure of a DTT session, children deficient in social, communication, and leisure skills are likely to return to their self-maintained repertoires of stereotypic behavior. This off-task behavior during unstructured or unsupervised activities may represent a problem of stimulus control. The conditions under which reinforcement contingencies are applied during teaching (presence of a teacher and treatment setting) acquire discriminative properties and occasion appropriate behavior. The absence of these stimuli may signal to the child that the controlling contingencies are no longer in effect.

For any skill to become functional, programming must ultimately result in the generalization of behaviors acquired in a specific training situation to a wide variety of other training environments and to the natural environment (stimulus generalization). Skills taught are more likely to be maintained and to generalize if practitioners teach to fluency rather than to accuracy, teach socially meaningful behaviors, and program for generalization.

Unlike DTT, which defines mastery as accuracy (typically measured as percentage correct performance), precision teaching focuses on the rate and endurance of learning. *Fluency* is a time-based measurement procedure that combines accuracy with speed of performance. Accurate but dysfluent performance requires continued training to improve retention and endurance of sustained performance. Fluent performance is more likely to be applied to a variety of situations, adapted and combined in new learning situations in the absence of instruction (Binder, 1996; West & Young, 1992).

Teaching socially meaningful behaviors can result in the development of skills that are maintained by natural contingencies in the home and community. Although speech and language development is a major focus of education programs for children with autism, the importance of participating in family life must not be dismissed. Engagement in productive and socially meaningful behavior that competes with the child's repertoire of inappropriate behaviors can be promoted by including the child in family activities (e.g., table setting, snack preparation, and trips to the grocery store). Teaching independent skills allows children opportunities to practice and maintain more appropriate repertoires of behavior without adult supervision. Independent engagement in self-care, work, and leisure activities have been taught using picture activity schedules (Krantz, MacDuff, & McClannahan, 1993; MacDuff et al., 1993) and time-delay procedures (Griffen, Wolery, & Schuster, 1992). Supervision that is scheduled intermittently and unpredictably will increase independent on-task responding.

New behaviors not specifically trained (response generalization) must be developed as well. Establishing discriminative control of behavior by common stimuli (curriculum materials and activity schedules) that can be used in home settings can maximize generalization of skills taught in the classroom. Additional strategies for promoting the generalization of behavior include teaching multiple examples of the behavior in different settings with different people and varying the noncritical dimensions of the teaching procedure (orientation of the student's desk, voice tone, presence of distractors, lighting conditions, and time of day). A similar strategy for programming response generalization is used to address the robotic characteristics of speech or the stereotypic play sometimes exhibited by children with autism. Creativity, like any response characteristic, can be taught if the contingencies of reinforcement "pay off" more heavily for performing a variety of responses during training (Winston & Baker, 1985).

It is essential that parents participate in the teaching process. Training parents to be teachers has several advantages. Children with autism exhibit severe deficits that persist beyond the limited number of hours of school programming. Parents have the greatest contact with their children, because the majority of their children's day is spent at home. Teaching parents to become behavior change agents extends the learning opportunities across a child's entire waking day and allows parents and other caregivers to teach functional skills in natural environments where they will be performed.

Also, parent training is essential if gains made in school settings are to generalize into the home environment and maintain over time. Generalization from the school to home is more likely to occur if parents are trained in settings where the skills are acquired and if teaching includes common stimuli that are found in the home and community. Parents must develop appropriate teaching skills and establish naturally occurring contingencies of reinforcement to facilitate generalized responding to new people, behaviors, and situations. They must be empowered to maintain existing skills over long periods of time, and develop new skills in the home and in the community that will foster greater independence for their children.

Reducing Inappropriate Behaviors

Learning theory provides the behavior analyst with several direct and indirect procedures for reducing the frequency of undesired behaviors. Two frequently used, but often misunderstood, response reduction procedures are *extinction* (the termination of a positive reinforcer) and *punishment* (the contingent presentation of an aversive consequence). Undesired behaviors acquired and maintained through positive reinforcement will decrease when reinforcement is terminated, unless there are other sources of reinforcement available for the behavior. If the reinforcers that are withheld are not the ones that maintain the behavior, responding will not be reduced.

Punishment can reduce undesirable behavior, with immediate suppression occurring, providing the intensity of the punishing stimulus is high enough. The side effects associated with punishment, however, argue strongly against its use:

- The effect of punishment depends on the intensity of the punishing stimulus (Azrin & Holz, 1966). At lower intensities, the suppressive effect is short-lived.
- Termination of punishment may result in a return to previous levels, or even in higher levels of undesired behavior than the unpunished level.
- Punishment is situation specific and frequently fails to generalize.
- Punishment produces an undesirable emotional state, including aggression toward the punishing agent (Azrin & Holz; Foxx, 1982).

- Parents and teachers who use punishment to control behavior not only model aggressive behavior that is likely to be imitated by the child (Bandura, 1969) but also risk becoming conditioned punishers. The child whose behavior is punished learns to escape or avoid the punishing parent or teacher, markedly weakening the reinforcing relationship needed to develop more appropriate alternative behaviors.

When designing procedures for reducing problem behaviors (aggression, self-injury, tantrums, and stereotypic behaviors), the context in which the problem behavior occurs must be examined (Brown et al., 2000; Carr & Durand, 1985; Durand & Carr, 1987, 1992). Problem behaviors can be maintained by either positive reinforcers (i.e., attention-seeking behavior) or negative reinforcers (i.e., escape from a difficult task). Serious behavior problems may occur because more appropriate skills, such as asking for assistance, were never taught. Systematic observation of the antecedents and consequences of behavior (i.e., functional analysis) permits an assessment of the purpose of the behavior, including consideration of possible communicative function.

A functional analysis helps to identify the causes of the behavior and can assist in preventing a problem or in selecting an effective treatment. Prerequisite skills or alternative verbal responses ("I want help") can be taught and reinforcers for inappropriate behaviors withdrawn. A mistake that educators and parents often make is attending to undesirable behaviors rather than reinforcing more appropriate competing alternatives. Unlike the immediate but short-lived effects of punishment, a positive educational approach to behavior management that emphasizes skill acquisition provides the learner with a repertoire of alternative behaviors that can be maintained by natural contingencies in the environment, with the added benefit of restoring dignity to the learner.

CURRICULUM DEVELOPMENT AND INSTRUCTIONAL METHODS

This section is designed to create an understanding of critical issues related to curriculum development for students with autism. Curriculum goals and objectives are discussed, and strategies for teaching new skills are described. Instructional programming should be focused on building a repertoire of skills needed to function productively within the mainstream of school and community. Curricular areas discussed in this chapter include social interaction, community living skills, and academics.

Over the past few decades, research has yielded much information about how to teach individuals with autism. Instructional technology for children

with autism has become increasingly sophisticated as public awareness regarding this disorder has grown. Parents, especially, have been effective advocates for the development of appropriate educational programs for their children. Whereas a few years ago, one would have been hard-pressed to find information pertaining to curriculum design for students with autism (Klatt, 2003), today journal articles and new books abound with descriptions of procedures for teaching new skills and reducing challenging behaviors.

The information presented herein represents the culmination of an ongoing comprehensive review of the autism literature, combined with observations gleaned from extensive school consultation service, years of experience teaching and administering special education programs, and more than 2 decades of teacher preparation in the field of autism. And, yet, we recognize that there is still a great deal more to learn about how to teach and succeed with students with autism.

Social Interaction Skills

Difficulty in forming relationships with other people constitutes a central feature of autism. Considerable attention has been devoted to designing strategies for improving the social functioning of individuals with ASD (see, e.g., Keeling, Myles, Gagnon, & Simpson, 2003; Matson & Swiezy, 1994). Children with ASD experience problems in interpreting and responding effectively to their social world (Gray, 2000). From their perspective, the statements and actions of others may seem to occur without reason and without warning. Whereas most people develop social competence through experiencing everyday interactions, individuals with autism often are unable to absorb this kind of knowledge without the benefit of direct skill instruction. In fact, in order to develop skill in social interaction, instruction must be extremely structured and systematic.

Curriculum content for building interpersonal social interaction skills should be based on a combination of developmental (Dyer & Peck, 1987) and behavioral theory (Lovaas, 2003). Advances in the field of autism have indicated the importance of the analysis and identification of the communicative intent of interactive behaviors (Christof & Kane, 1991; Donnelan, Mirenda, Mesaros, & Fassbender, 1984; Durand, 1990), in recognition of the fact that every interpersonal behavior, regardless of its outward form, is inherently meaningful.

Where to Begin—Teaching Play Skills

The play of children with ASD is strikingly different from that of typically developing children. Flexibility and spontaneity are often lacking in

interactions, and symbolic pretense tends to be conspicuously absent. The play of children with autism is often perseverative and rigid in routine. There may be a tendency to manipulate objects in stereotypic manner. In addition, children with autism have difficulty engaging in mutually supported play activities.

Planned peer play experiences under structured supervision can foster the development of communication and socialization. Shared enjoyable and satisfying experiences with other children are vital to the success of a social skills program. Applied behavioral techniques, in combination with developmentally appropriate goals and activities, will lead to the establishment of a repertoire of usable social interaction skills. In order to plan social skills instruction, detailed information must be obtained pertaining to the child's functioning level, home and school environments, and personal preferences.

Research and experience indicate that in order to teach social interaction and play skills to students with autism, instruction must be highly structured and real-life experiences need to be incorporated into the program to foster generalization and maintenance. In addition, physical ecological conditions have a significant impact on the development of social interaction skills (Quill, 1995). For instance, play spaces should be sufficiently large to accommodate the necessary size of the group while small enough to avoid large open spaces. Overcrowding can create conflicts; yet too much space can lead to lack of interaction. Important also, is that the teacher, paraprofessional, or other individual supervising the play activity be as inconspicuous as possible and refrain from nonproductive interference in the social activity.

Effective social skills training programs may incorporate aspects of a variety of programs and approaches into one cohesive program for each child. A widely employed method for teaching social skills involves the development of social stories and social scripts. A social story is considered a process that results in understanding a social situation and having a strategy or means to deal successfully with that situation. Social stories can be written by parents, teachers, therapists, psychologists, or other service providers to improve the social understanding of individuals on both sides of the social equation. They can be employed to address an infinite number of topics. Typically, these stories are prepared in response to troubling situations, but they might be better utilized to prevent such situations by anticipating issues that might arise prior to the incident. For example, if a class is planning a trip, perhaps rules for bus behavior could be the basis for a social story. Over 100 social stories dealing with polite amenities, personal care, mealtime routines, domestic chores, school behavior, transportation, and games and activities can be found in *The New Social Story Book* by Carol Gray (2000).

Another interesting approach for improving social skills, especially useful for students with Asperger's syndrome and HFA, is the provision of

experiential social activities (Forgan & Jones, 2002). Teachers and parents can utilize experiential adventure games, problem-solving initiatives, and trust-building activities from the early years through adulthood. Such activities help to develop an atmosphere of acceptance, one in which students are more likely to work and learn cooperatively. Because children with autism typically do not understand abstract concepts about helping, sharing, turn taking, sportsmanship, empathy, or reciprocity, actually experiencing situations is by far the most effective mode of instruction. This applies not only to social skills training but also to other areas of instruction.

The experiential social problem-solving approach focuses on teaching generalizable behaviors, rather than on discrete skills, with the premise that once children have learned skills related to cognitively solving interpersonal issues, these skills will be reapplied successfully again and again and will result in the improvement of social behavior. In a meta-analysis of more than 95 studies pertaining to experiential social skills training, Hattie, Marsh, Neill, and Richards (1997) found higher levels of skill maintenance based on consistent program development.

In combination with other approaches, especially systematic applied behavior analytic techniques, experiential adventure social skills training can lead to acquisition, generalization, and maintenance of appropriate and productive interpersonal behaviors. As with any methodology that has not been designed specifically for children with autism, modifications to the general structure of activities is necessary. For example, although much of traditional adventure curriculum depends on lengthy sensitive discussion of issues that arise during activities, this type of discussion can be counterproductive for students with ASD.

Applying social stories in combination with contingency contracting is another useful strategy to increase the likelihood of enjoyable interactions between children with autism and nondisabled peers. It is usually natural for people to arrange contingencies in an informal manner. Most of us do not predetermine when we will deliver reinforcement in particular situations. It just happens. But when teaching children with autism new behaviors, it is imperative that we establish a very structured contingency system in which the behaviors that we wish to change are clearly defined and reinforcement contingencies are specified.

A contingency contract is an agreement between two or more people that lists specific behaviors that the contracting parties will perform and the resulting consequences of these behaviors. Behaviors and reinforcers are clearly delineated. The goal of the contract is for reinforcement to be exchanged among the participating individuals. In order for a contingency contract to work, it must include information about who is responsible for which behavior, when the behavior should occur, what the consequences will be, who will deliver the reinforcement, and when each action included

in the agreement will take place. The contract should be written in positive terms and in such a manner as to ensure success.

Social situations can be altogether perplexing for children with autism. Play is often symbolic in nature, which constitutes a major problem for individuals who do not understand or relate to abstract concepts. Prior to commencing instruction in any area, it is important to identify and target skills that are important for the child to learn. Appropriate and thorough assessment (refer to chap. 8, this volume, "Assessment of Children with Autism") helps teachers to determine which skills need to be taught, which are priority skills, at what level to begin instruction, and how best to teach each child. Finally, providing instruction in a supportive setting with consistency and predictability will enable children to engage in social activities with a sense of comfort and control over their environment.

Community Living Skills

In order to prepare individuals for successful community integration, curriculum content must include skills that are relevant to the actual living needs of students. Proficiency in community living social skills can enhance the quality of life for individuals with autism by enabling them to participate in activities in their communities.

As youth with autism begin to focus more and more on the transition from school to employment and adult living, social skills take on a different dimension. It is far easier to train an individual with autism to perform job-related skills than to teach the wide array of social skills required at a work site. Such social skills training can be successful only if it is begun in the early school years with lessons in attending to and completing tasks, following instructions, taking pride in one's work, dressing appropriately, requesting assistance when necessary, eating in a lunchroom politely, and so forth. Also, social skills instruction for employment must be delivered in the community where the skills will be utilized. Therefore, a part of the school day for secondary students with autism who will be working after graduation should be spent at job sites where the students will learn actual job skills combined with real-life social skills.

Self-Preservation (Safety) Skills for Community Living

Self-preservation, or safety skill training, is designed to improve students' ability to recognize and appropriately respond to dangerous, and possibly life-threatening situations at home, in school, and in community settings. Self-preservation skills include certain abilities associated with one's lifelong maintenance in the community.

Self-preservation skills should be assessed for each student prior to beginning instruction. Based on an ecological inventory of the environments in which individuals spend significant portions of their daily life, these skills should be prioritized and taught with long-term planning in mind. Ecological inventory strategies require that teachers visit and obtain relevant information about the environments in which students are, or may be, expected to function. Some examples of instructional objectives in the area of self-preservation are:

1. Student keeps foreign objects out of eyes, ears, nose, and mouth.
2. Student maintains safe distance from stove.
3. Student refrains from touching electrical outlets or wires.
4. Student dials police emergency number.
5. Student follows rules during fire drill.
6. Student handles sharp objects carefully.
7. Student recognizes and follows safety signals (e.g., red light).
8. Student looks both ways before leaving sidewalk to cross street.
9. Student remains seated in car or bus.
10. Student keeps seatbelt fastened in car or bus.

Daily Living Skills

Preparing students with autism to become contributing members of their home environment requires that families and educators work together to develop appropriate programming in daily living skills that are suited to each students' particular situation. Daily living skills include basic living activities and domestic care. Eating, toileting, dressing, and grooming constitute basic living activities. Domestic care involves responsibilities related to maintaining a clean and pleasant home environment. Proficiency in these activities will enable individuals to function as independently as possible. Instruction in daily living skills should start early in life and be developed systematically with the changing needs of the student and the home environment.

Critical to successful instruction in activities of daily living is the utilization of the student's own home to ensure that the student will be able to perform these activities where and when necessary. Concomitant instruction at both home and school is ideal. In order to select and prioritize instructional objectives, information from the student and the family must be obtained regarding preferences, current living arrangements, future plans, and present level of functioning. Assessment of the student's daily living skill repertoire is required prior to the onset of training and throughout the training process.

ACADEMIC INSTRUCTION

As the diagnostic category of ASD has broadened and expanded, so has the range of ability level among students in this category widened. This section includes information pertaining to instruction in functional academics for individuals with significant cognitive impairment, and also addresses differentiation of instruction and curriculum modification for students with HFA and Asperger's syndrome with average to superior intelligence, who may require accommodations in general education classrooms.

Teaching Functional Academics to Students With Autism

Many students with autism function cognitively within the moderate to severe mental retardation range. Curricula for students with severe disabilities have traditionally been organized into categories, such as self-help skills; language development; recreation, leisure, and social skills; and functional academics. Basic reading and math skills needed for everyday living constitute the core of functional academic programs. Academics are functional when they involve such skills as knowing coin values; using a calculator to add up purchases; telling time; writing a signature; or reading words like *in, out, exit,* and *walk* when they are encountered outside of school.

Functional academic skills are useful in several life space domains. For example, making change might be useful in a restaurant, supermarket, clothing store, and bus, or at a pay telephone and vending machine. Because generalization is often a problem for individuals with autism, functional academics should be taught in particular environments in which they will need to be performed.

Using naturally occurring cues and reinforcers will lead to increased transfer of skills. When instruction is provided in environments where the targeted skills naturally occur, difficulties in generalizing skills from simulated to natural environments are reduced. By employing direct instruction in a variety of community-based sites, educators make no inferences regarding skill generalization from the training site to real-life situations. Students taught to perform skills only in artificial settings, such as simulated supermarkets, have really not been taught to perform functional skills because they may not be able to transfer the skills to nonschool environments.

In order for students to gain competence in functional academics, or any other skills that will be used in the community, the amount of time spent within the confines of the classroom must decrease. Training should take place, as often as possible, in the specific locations in which students will be expected to function. Students need to learn to interact not only with teachers and family members, peers, and school personnel, but also with

strangers, such as waiters, store clerks, bus drivers, physicians, and numerous other people within the community. Community environments offer a rich variety of situations to which students must learn to respond. Teaching procedures that draw the student's attention to relevant cues as they naturally occur in the community can facilitate learning, as well as skill generalization and retention. Only through the provision of onsite community-based instruction will educators attain success in teaching community living skills.

Parental input is valuable for gaining insights into the student's lifestyle, preferences, interfering or dangerous behaviors, and financial resources available for visiting particular places. School administrators may lend support to community-based training through budget allocation, as well as through personal interest and activity in the program. In order for administrators to understand and appreciate the benefits of such training, on-site observation is helpful.

When selecting community environments for instruction, several factors should be considered (Falvey, 1989). Specifically, the following questions should be addressed:

1. Is the type of environment being considered frequented by students with family members and/or caretakers during nonschool hours?
2. Is the environment frequented by nondisabled peers?
3. What types of environments are preferred by particular students?
4. Does the environment involve skills that would be required in other community environments?

Task Analysis

The second step in the instructional process, following curriculum development, is the designing of instructional procedures. Curriculum deals with the question of "what to teach," whereas task analysis answers questions regarding "how to teach." *Task analysis* is the breaking up of a task into its component parts, or subskills, and placing these subskills in sequential order. Task analyses organize the activities, or tasks, into teachable steps and strategies for instruction. They enhance instruction by ensuring that essential subskills are taught, tailoring instruction to individual functioning, and keeping the teacher and student on track by reducing the likelihood of teaching unnecessary skills. When properly utilized, task analysis can thus lead to more effective programming.

Behaviors in a task analysis must be stated operationally (i.e., in terms of observable movement that is measurable). All behaviors should be stated in terms of learner action so that what is to be learned and how it is to be taught provide the focus at this stage. In addition, each step of the task analysis

should be stated discretely so that it can be separated from the other steps and can stand alone for instructional purposes. A complete task analysis includes the following types of information:

1. Statement of performance objective, or task to be learned
2. Antecedent cue to let the student know what is expected
3. List of necessary resources and materials
4. List of subskills necessary to master the performance objective

Helpful Tips for Instruction of Students With High-Functioning Autism

Students with HFA or Asperger's syndrome in inclusive settings may run into difficulty with abstract types of learning tasks, lengthy directions, personal and social interactions, test anxiety, social isolation, and so forth. They often adhere rigidly to rules, may tend to be extremely literal in interpretations, react with distress to unexpected changes in routines, may become distracted before completing tasks, and have difficulty with transitioning between activities. Although they may be functioning on or above grade level in some or all of their academic subjects, their behavioral quirks often interfere with their progress and inhibit their success.

Creating a supportive learning environment is an essential component to school success for students with HFA. It may be helpful to provide support through visual aids (e.g., schedules, charts, signs, and lists). Such supports are especially useful in facilitating transitions. They are helpful in redirecting and refocusing students who have difficulty staying on task. Task organizers based on task analyses can assist students to progress through tasks. These task organizers function in a manner, similar to that used in cookbook recipes, that can be reviewed prior to doing an activity, ensure that the student has all the needed materials to complete the activity, and guide the student through the activity. Pre-teaching in this fashion, enables students to enjoyably engage in lessons with their classmates.

Because students with autism often have language-processing difficulties, it is helpful to slow down the pace of directions, keeping language lean and refraining from cute unfamiliar twists of language, which tend to result in confusion. Be clear, brief, and precise in expectations, and when necessary, script and rehearse behaviors for new situations. Make sure that the student is attending when you begin instruction. If the student misses the beginning of a lesson, the potential for failure is great. Be consistent with directions. In new tasks, provide clear, visual prompts within the instructional stimuli (e.g., color cue short and long clock hands). Reinforce correct responding frequently to provide assurance to students that they are on the right track. Then fade prompts and thin reinforcement as appropriate.

Integrated Behavioral Experiential Teaching

For children with learning differences, including ASD, it is clear that the most effective methods of academic instruction include applied behavior analytic techniques in combination with learning tasks that are relevant and meaningful. A sure-fire way to provide relevant and meaningful learning tasks is to use the child's own experiences as the basis for lessons. By using the child's actual experiences as the raw material for reading, writing, and mathematics lessons, instruction becomes understandable and fun. The student feels empowered as a partner in the learning process, and self-esteem is improved. The motivational power of the lesson is enhanced because the student is providing material for learning that is of interest.

For reading instruction, photographs can be brought to school, or taken at school, to use as the basis for stories. By combining real-life experiences with multisensory techniques (e.g., Fernald and Orton) that present information through visual, auditory, kinesthetic, and tactile sensory channels, word attack decoding skills emerge more readily because the child has contributed the raw material for the story. Comprehension skills at the literal, inferential, and critical thinking levels make more sense if the student has actually experienced the story. Words studied in the story can be incorporated into language arts activities, including spelling, alphabetizing, and composition. Even mathematics can be integrated into the lesson, for certainly there are objects to count, analog clock times to decipher, money to be spent, and so forth. Student-produced stories are often inherently reinforcing because of their high interest level. When the learning task itself is reinforcing, learning occurs with fewer off-task or disruptive behaviors.

SUMMARY

The ultimate goal of education is to prepare individuals to lead productive and satisfying lives. Toward this end, educators need to take advantage of new information and advances in the field of special education. Recognition and utilization of documented effective practices, bearing in mind that there is no such thing as a one-size-fits-all recipe, will lead to advances in the education of autistic children.

Behavior analytic programs are geared toward creating success by attending to the specific learning styles of children with autism, providing students with as many opportunities as possible to learn, and by accepting responsibility for student progress. Classroom intervention should be based on teaching procedures that have been validated. An examination of the child's learning environment (i.e., antecedents and consequences) as it relates to behavior (i.e., learning outcomes) permits teachers to make empirically based decisions about the effectiveness of their teaching strategies.

Curriculum content should include life skills for community living, social and communication skill development, and academics presented through integrated behavioral experiential teaching. When planning IEPs, teachers must consider lifelong goals for their students. Learner styles should be accommodated as teachers prepare students, through systematic instruction in natural environments, to function in the real word.

Children with autism demonstrate multiple skill deficits and behavioral excesses that impede learning. When learning problems persist or appear resistant to treatment, teachers may look for explanations that are outside of their control and are not subject to direct manipulation. References to unobservable, hypothetical events operating within the child to explain these deficits and excesses often cloud the issues and add little to our understanding or identification of the controlling variables. In order for instruction to be effective, teachers need to recognize the unique learning history and skills of each child and identify relevant variables that can produce change. The key to teaching children with autism lies in the teacher's acceptance of responsibility for learning and the design of learning environments that support the growth of appropriate repertoires.

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Chapter 10

Enhancing Language and Communication Development in Autism Spectrum Disorders: Assessment and Intervention Guidelines

Amy M. Wetherby
Florida State University

Barry M. Prizant
Childhood Communication Services and Brown University

INTRODUCTION

The development of language and communicative abilities is a major challenge faced by persons with autism spectrum disorders (ASD). The significance of this challenge is reflected in current conceptualization of ASD, which includes language and communicative impairments as a primary diagnostic feature (American Psychiatric Association [APA], 1994). The presence of fluent speech, defined as using multiword combinations spontaneously, communicatively, and regularly before the age of 5 continues to be a good prognostic indicator of IQ, language measures, adaptive skills, and academic achievement in adolescence (Lord & Paul, 1997). The level of communicative competence achieved by persons with ASD is closely related to the development of social behavior (Garfin & Lord, 1986) and measures of outcome (Koegel, Koegel, Shoshan, & McNerney, 1999; McEachin, Smith, & Lovaas, 1993). Moreover, gains in communication skills are directly related to the prevention and reduction of problem behavior (Fox, Dunlap, & Buschbacher, 2000; National Research Council [NRC], 2001; Reichle & Wacker, 1993). The severity of the communicative impairment of children with ASD may be one of the greatest sources of stress for families (Bristol, 1984). Therefore, enhancing language and communicative abilities needs

to be a major focus in the provision of education and treatment for individuals with ASD and their families. This chapter provides an overview of the nature of communication and language difficulties experienced by persons with ASD. Guidelines for assessing communication and related symbolic abilities using ecologically based strategies are presented, and current recommended practices for enhancing language and social communication are suggested.

NATURE OF SOCIAL COMMUNICATION AND LANGUAGE DIFFICULTIES IN ASD

Major advances have been made over the past 2 decades in delineating and understanding the communication and social difficulties of children with ASD. This progress has resulted in a greater emphasis on early social–communicative patterns in the diagnostic criteria for ASD (American Psychiatric Association [APA], 1994). The communication and language impairments of persons with ASD range widely—from failure to develop any functional speech, to the development of functional but delayed and idiosyncratic use of spontaneous speech and language, to problems primarily in more advanced conversational skills, despite fully developed and complex language abilities (Lord & Paul, 1997). At least one third of children and adults with ASD have no speech (Bryson, 1996). For both verbal and nonverbal individuals, impairments in social aspects of language and related cognitive skills are the most salient (Lord and Paul; Wetherby, Schuler, & Prizant, 1997) and are described briefly in the following section.

The diagnostic characteristics of ASD are now understood to involve a triad of symptoms: (a) impairments of social interaction; (b) impairments of verbal and nonverbal communication; and (c) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities (APA, 1994). Research over the past decade has identified the following two core social and communication capacities that children with ASD have particular difficulties acquiring (Wetherby, Prizant, & Schuler, 2000):

1. *Joint attention*, which reflects difficulty coordinating attention between people and objects and is evident by limitations in (a) orienting and maintaining attention to a social partner, (b) shifting gaze between people and objects, (c) sharing affect or emotional states with another person, (d) following the gaze and point of another person, and (e) being able to draw another persons' attention to objects or events for the purpose of sharing experiences; and
2. *Symbol use*, which reflects difficulty learning conventional or shared meanings for symbols and is evident by limitations in (a) using

conventional gestures, (b) understanding and using conventional meanings for words, and (c) using objects functionally and in symbolic play.

Joint attention has been found to be a significant predictor of language outcome. Mundy, Sigman, and Kasari (1990) found that measures of gestural joint attention (e.g., showing or pointing to direct attention) at initial testing were a significant predictor of language development 1 year later for preschool children with ASD, whereas none of the other nonverbal measures, initial language scores, mental age, chronological age, and IQ were significant predictors. These findings were further substantiated in a larger follow-up study examining the communicative behaviors and language skills of more than 50 children with ASD between the ages of 10 and 13 (Sigman & Ruskin, 1999). Limitations in joint attention were closely linked with deficits in play, emotional responsiveness, and peer interactions. Accumulated data suggest that the failure to acquire gestural joint attention may be a critical milestone that impairs language development and an important target for early communication intervention.

Limitations in symbol use have been documented across modalities. Children with ASD do not compensate for limited verbal skills with gestures to the same extent as other children with language disorders (Wetherby, Prizant, & Hutchinson, 1998); rather, they show limited gestural use both in quantity and in quality. They predominantly use primitive motoric gestures (i.e., contact gesture of leading, pulling, or manipulating another's hand) to communicate. They demonstrate lack of, or limited use of many conventional gestures, such as showing, waving, pointing, and symbolic gestures, such as nodding head and depicting actions (Stone & Caro-Martinez, 1990; Stone, Ousley, Yoder, Hogan, & Hepburn, 1997; Wetherby et al., 1998; Wetherby, Yonclas, & Bryan, 1989). In lieu of conventional means of communicating, children with ASD may develop idiosyncratic, unconventional, or inappropriate behaviors to communicate, such as self-injurious behavior, aggression, or tantrums.

There is much variability in the capacity to use vocal communication, which likely contributes to the wide range of speech skills observed in persons with ASD. Some children have been found to use a limited consonant inventory and less complex syllabic structure, whereas others show adequate complexity of vocalizations (Stone & Caro-Martinez, 1990; Wetherby et al., 1989; Wetherby & Prutting, 1984). In a recent study of vocal behavior of preverbal children, Sheinkopf, Mundy, Oller, and Steffens (2000) found that compared to children with developmental delays, children with ASD used a comparable proportion of well-formed syllables containing consonants but a significantly greater proportion of syllables with atypical phonation, such as squeals, growls, and yells. The atypical patterns of vocal behavior were

independent of joint attention deficits but were negatively correlated with mental age, suggesting that the joint attention and vocal limitations arise from different pathological processes.

The vast majority of children with ASD who do learn to talk go through a period of using echolalia, the repetition of speech of others, which may be immediate or delayed (Prizant, Schuler, Wetherby, & Rydell, 1997). An echolalic utterance is usually equivalent to a single word or a label for a situation or event, and appears to reflect limitations in symbolic capacity. Many children learn to use echolalia purposefully in communicative interactions, and eventually are able to break down the echolalic chunks into smaller meaningful units as part of the process of transitioning to a rule-governed, generative language system (Prizant & Rydell, 1993).

Further evidence of limitations in the symbolic capacity in ASD is the limited ability to develop symbolic or pretend play. Although play is a social–cognitive skill, it is noteworthy that a lack of varied, spontaneous make-believe play is one of the four possible features of the impairment in communication in the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition (*DSM-IV*; APA, 1994). Children with ASD have significant difficulties engaging in symbolic or make-believe play (i.e., using pretend actions with objects) and limited abilities in functional play (i.e., using objects functionally; Dawson & Adams, 1984; Sigman & Ungerer, 1984; Wetherby & Prutting, 1984; Wing, Gould, Yeates, & Brierly, 1977). Functional and symbolic play skills have been found to be significantly correlated with receptive and expressive language (Mundy, Sigman, Ungerer, & Sherman, 1987; Sigman & Ruskin, 1999). In contrast to deficits in functional object use and symbolic play, children with ASD perform at similar or higher levels on constructive play (e.g., using objects in combination to create a product, such as stacking blocks, nesting cups, or putting puzzles together) compared to typically developing children or children with language delays at the same language stage (Wetherby et al., 1998; Wetherby & Prutting).

Exploring developmental profiles of strengths and weaknesses in communication and symbolic abilities has contributed to better understanding of the nature of these problems in ASD. Studies by Stone et al. (1997) and Wetherby et al. (1998) examined the developmental profiles of 2- to 4-year-old children with ASD compared to children with delayed language (DL) who were at the same language stage. Using similar strategies for gathering communication samples, these researchers reported a similar profile in children with ASD characterized by a distinct constellation of strengths and weaknesses in parameters of communication. More specifically, the children with ASD showed comparable or higher use of communication to request and protest, but significantly less use of gaze shifts, shared positive affect, conventional gestures, coordinated gestures with vocalizations and eye gaze, and communication for joint attention. The children with ASD performed

at comparable levels of constructive play but significantly poorer levels of language comprehension and symbolic play. Correlational findings from the Wetherby et al. study showed that children who displayed a greater capacity to coordinate attention and affect were more likely to communicate for more social reasons, to use a larger repertoire of conventional gestures, and to use a higher rate of communicating.

In summary, research over the past 2 decades has clarified the nature of the communication and language impairments. These findings suggest that there is a constellation of limitations in communicative and symbolic behaviors, including deficits with gaze shifts, shared positive affect, joint attention, conventional and distal gestures, rate of communicating, language comprehension, and symbolic play (Wetherby et al., 1998). These core deficits offer a framework for individualizing child goals and documenting meaningful outcomes for young children with ASD. Efforts to enhance social and communication skills for children with ASD should focus not only on increasing gestures, vocalizations, and verbalizations (i.e., the means used to communicate) but also on increasing social communication abilities. These abilities enable children to initiate interactions and participate actively in social exchange with the vocalizations, gestures, or words they have for a variety of communicative functions (i.e., communicative functions or social–pragmatic abilities). These patterns of limitations provide a challenge both for professionals designing intervention programs for individuals with ASD and for family members supporting their development. Furthermore, such patterns suggest that effective intervention programs should address and document progress in these core deficits of joint attention and symbol use. In other words, the efficacy of communication intervention should be determined by meaningful outcome measures in social communicative parameters, not just by the development of vocal and verbal behavioral repertoires.

MAJOR CONSIDERATIONS IN COMMUNICATION PROGRAMMING

Numerous issues need to be taken into consideration in developing individualized communication programs for persons with ASD. The issue of developmental appropriateness of communication goals and strategies needs to be addressed. The developmental literature provides a rich theoretical foundation for both understanding communication problems and for implementing effective and developmentally appropriate interventions. Wetherby et al. (1997) identified three significant principles drawn from the developmental literature that are critical for persons with ASD. First, communication development involves continuity from preverbal to verbal communication. That is, the development of preverbal communication is a

necessary precursor to the development of the intentional use of language to communicate. Words should be mapped onto preverbal communication skills. For individuals with ASD who do not talk, emphasis should be placed on developing preverbal social and communication skills. Second, being a competent communicator is the outcome of a developmental interaction of cognitive, social-affective, and linguistic capacities. An individual's developmental profile across these domains should provide the basis for decision making for communication enhancement. Third, in a developmental framework, all behavior should be viewed in reference to the individual's relative level of functioning across developmental domains. Many of the problem behaviors developed by individuals with ASD can be understood as attempts to communicate if such behavior is interpreted relative to developmental discrepancies and as coping strategies in the face of significant communicative limitations.

The issue of chronological age and impending life transitions that the individuals with ASD and their families face is another major consideration that influences decisions made when developing a communication program. Decisions about goals to target and strategies to use for enhancing communication will differ for infants and toddlers, preschool children, school-age children, adolescents, and adults. At younger ages, developmental appropriateness does not usually conflict with chronological-age appropriateness, and therefore, developmental issues become paramount. That is, early developing communicative skills of typical children are appropriate and functional for young children with ASD, therefore, are appropriate targets in intervention. For older children, adolescents, and adults, functional considerations may need to take priority, especially for individuals who may acquire only limited communicative abilities due to the severity of their disability. However, the individual's developmental level in communication and language can be used as a frame of reference for targeting functional skills.

Another factor influencing communication programming is the social support available to the family. Caregivers' ability to enhance communication abilities will be influenced by formal and informal supports available to them (Bristol & Schopler, 1983; Dunst, Lowe, & Bartholomew, 1990). Stresses on the family change with the child's age; thus, issues regarding family support are related to the child's chronological age. For younger children, families may just be beginning to experience a grieving process, and may be undergoing dramatic shifts in emotional well-being (Domingue, Cutler, & McTarnaghan, 2000; Moses, 1983; Prizant & Tiegerman, 1984). Development of communication is critical for younger children, as it relates to day-to-day stresses of the family and to long-term prognosis. For older children and adolescents, stresses on the family have been found to be even

greater, due to the family's acceptance of their child's disability and their pessimism regarding outcome, and the great demands on family involved in caring for an older person with ASD (Bristol & Schopler, 1983). Because of the severity of the disability associated with ASD, it is critical that communication programming addresses skills that will enhance the individual's ability to be a more effective, independent communicator across settings and partners (Prizant, Wetherby, Rubin, & Laurent, 2003).

Another important factor is the setting or context in which communication programming will occur. For younger children, communication programming is usually either center based or home based, therefore, decisions pertain to how to best address the communication needs of the family (see Wetherby et al., 1997). For school-age children, considerations depend on whether the child is educated in an inclusive versus a segregated setting. With the trend toward inclusive education, issues relating to the chronological age of the child and peers become more critical for school-age children (see Burack, Root, & Zigler, 1997). In adolescence and adulthood, programming issues relate to whether educational, vocational, and living environments are segregated or in more restrictive settings, or located within community settings. Because communication development should be facilitated in all natural settings, the issues pertaining to the setting will affect communication goals and strategies.

ASSESSMENT GUIDELINES

Traditional formal language assessment instruments focus primarily on the structure of language and rely on elicited responses. Because language impairments associated with ASD are most apparent in social aspects of language, formal assessment instruments have limited utility (Prizant et al., 1997; Schuler Prizant, Wetherby, 1997; Wetherby et al., 2000). Therefore, professionals must rely on the systematic use of informal procedures to assess language and communication. Communicative abilities of persons with ASD need to be examined in a variety of natural communicative exchanges, with theirolic abilities serving as a developmental frame of reference (Wetherby et al., 1997). The primary goal of assessment is to provide information that can be directly translated into goals, strategies, and outcome measures for communication enhancement. In designing an assessment plan, the domains to be assessed need to be determined first, and then strategies to explore these domains can be planned. This section provides a framework for an individualized assessment of communication and symbolic abilities for persons with ASD based on the three core assessment domains delineated by Wetherby and colleagues (1997).

Assessment of Communicative Abilities

Communication and Language

An assessment of communication should identify the repertoire of communicative means or behaviors used to express intentions. Because persons with ASD often use unconventional, idiosyncratic, or problem behavior to communicate for various functions (Carr & Durand, 1986; Donnellan, Mirenda, Mesaros, & Fassbender, 1984; Prizant & Wetherby, 1987; Wetherby & Prutting, 1984), the degree of conventionality, readability, and social acceptability should be considered for the individual's repertoire of communicative behaviors. A lack of conventionality or social acceptability should not preclude the possibility that a behavior is used purposefully to communicate.

The individual's capacity for using gestural and vocal communication should be compared to guide decisions in selecting and enhancing communication systems. Gestures may range from primitive contact gestures, in which a person physically manipulates another person's hand, to distal gestures, in which there is no physical contact, such as distal pointing or waving. Vocalizations may range from vowels that are differentiated based on the emotional state expressed (e.g., pleasure versus distress) to articulated speech. Gestures and vocalizations may range from presymbolic behaviors to symbolic, referential communication. A developmental framework summarizing major milestones in language production and comprehension is presented in Table 10.1 and can be used to identify the level of an individual's communicative and language abilities to guide decisions in prioritizing intervention goals. However, determining the level of language production for individuals with ASD may be difficult, particularly when rote memory capacity for learning language forms exceeds comprehension of these forms, as is observed in echolalia. It is not simply a matter of determining whether an individual is preverbal or verbal, but rather, examining how gestures, sounds, words (spoken or signed and echolalic or creative speech), and word combinations are used.

Professionals and caregivers need to be knowledgeable about the language level of a person with ASD in order to form reasonable expectations about the individual's language capabilities. Four major questions should be asked in considering level of language production. First, what communicative means (i.e., gestures, sounds, and words) does a person use that serve communicative purposes, and are these used intentionally? Second, are words used, and if so, do the words have referential meaning? That is, are words used to refer to specific objects or events in a relevant manner, and only those objects or events? Individuals who use words or word combinations communicatively but not referentially will typically cycle through

TABLE 10.1
Major Stages of Language Development

Intentional Communication: 9–13 Months

- Uses gestures and vocalizations to communicate intentionally in order to regulate other's behaviors, to engage in social interaction, and to reference joint attention
- Demonstrates nonlinguistic comprehension strategies, including comprehension of nonverbal (gestures, facial expression, and directed eye gaze), situational (immediate environment and knowledge of what to do with objects), and paralinguistic (intonation) cues

First Words: 13–18 Months

- Uses a small number of conventional signals referentially, i.e., to refer to objects or classes of objects
- Shows slow vocabulary growth with some attrition of vocabulary; inventory of words usually does not exceed 10 to 20 single words at one time
- Increases use of gestures and sounds in coordination to communicate intent
- Most words are used to encode the semantic relations of existence, nonexistence, recurrence, & rejection
- Repairs unsuccessful communicative interactions by repeating, modifying the form, or using an alternative strategy
- Develops comprehension of single words to direct attention to relevant objects or to suggest actions appropriate to the immediate environment

First-Word Combinations: 18–30 Months

- Shows a sudden surge in vocabulary growth from a few dozen to several hundred words; vocabulary attrition should no longer be evident
- Shows expansion of single-word semantic relations (e.g., action, attribute, denial, location, possession)
- Uses word combinations to encode semantic relations (e.g., action + object, agent + action, attribute + object, action + location, possessor + possession)
- Uses words and word combinations for predication, i.e., to encode a state, quality, or relation about an object
- Uses imitation as a predominant strategy in language learning
- Begins to engage in conversation by providing new information about the previous speaker's topic, requesting information, and providing information about things in the past
- Comprehends word meanings but depends on immediate environment, knowledge of prior similar experience, and knowledge of semantic relations to know how these elements go together.

Sentence Grammar: 30 Months–5 Years

- Uses language to regulate own and other's actions, plan and anticipate outcomes, report on present and past experiences, comment on imagined context, project own and other's feelings, and regulate interactions; expresses more than one function in a single utterance
- Develops semantic relational terms to encode spatial, dimensional, temporal, causal, quantity, color, age, and other relations
- Uses grammatical morphemes (e.g., prepositions, tense markers, plural endings, pronouns, and articles)
- Uses syntax (i.e., rules of word order) to construct declarative, negative, imperative, interrogative, passive, and complex sentences
- Comprehends sentences based on morphological and syntactic rules (e.g., uses word-order strategy for agent–action–recipient relations)

(Continued)

TABLE 10.1
(Continued)

Discourse Grammar: 4–8 Years
• Learns to abide by conversational rules to be clear, informative, and polite
• Produces connected discourse by setting up transitions between sentences and clarifying shifts in reference from one clause or sentence to another to convey personal experiences and tell stories
• Comprehends connected discourse by using knowledge of scripts and story grammar to comprehend narratives
• Develops metalinguistic awareness of language structure and meaning, i.e., ability to focus attention to both language form and content; develops skills such as making grammatical judgments, resolving lexical ambiguity, using multiple meanings of words in humor, and segmenting words into phonemes

Note. Adapted from Bates, O'Connell & Shore (1987); Prizant & Wetherby (1993); and Wetherby & Prizant (1992).

their repertoire of utterances in an attempt to request an object until they produce the correct label, resulting in the partner providing the desired object.

A third question to be explored in considering an individual's language level is how many different words and word combinations are used referentially. For an individual with ASD who is producing spontaneous or echolalic utterances, the inventory of utterances used referentially may be a better measure of language level than utterance length or complexity. If an individual spontaneously produces less than 20 different utterances, it is likely that his or her overall language level is within *first words*, rather than within *first-word combinations.* A fourth question for persons who use word combinations is: Do they use the individual words alone and in other word combinations, or is an utterance equivalent to a single word for that person? It is likely that persons who do not combine words creatively are functioning within first words, rather than within first-word combinations, even though they produce multiword "units" or "gestalt forms" (Prizant & Rydell, 1993). Although this seems paradoxical, it is important to determine an individual's generative language capabilities and not be misled by the surface form of utterances that may give a misleading picture of linguistic competence.

It also is important to assess level of language comprehension so that professionals or significant others can use this information to adjust their language level to promote successful interactions. As outlined in Table 10.1, it should be determined whether the child's language comprehension is at a prelinguistic or linguistic level (see Lord, 1985). At prelinguistic levels, an individual may comprehend and respond to a message based on nonverbal, situational, and paralinguistic cues. It is important for professionals and significant others to be aware of whether these nonlinguistic cues are necessary to understand the message. For individuals who comprehend linguistic

aspects of the message, it is important to determine whether the individual is able to comprehend single words within the message, multiwords guided by semantic relations (i.e., understanding based on knowledge about word classes and relations), grammatical constructions (i.e., syntactic and morphological rules), or connected discourse.

Sociocommunicative and Socioemotional Abilities

Because the lack of joint attention is a hallmark of ASD, it is important to determine the range of communicative functions expressed by the individual. If an individual is at a preintentional level (i.e., does not demonstrate any deliberate, goal-directed communication), assessment should identify any behaviors that serve a communicative function based on others' interpretation of these behaviors. For individuals demonstrating intentional communication, assessment should identify the range of communicative functions expressed. A framework that is useful in assessment is based on Bruner's (1981) categories of communicative functions that emerge in development prior to the onset of speech.

1. *Behavior regulation* includes communicative acts that are used to regulate another's behavior for purposes of obtaining or restricting environmental goals (e.g., request or protest object or action).
2. *Social interaction* includes communicative acts that are used to attract and maintain another's attention to oneself for affiliative purposes (e.g., request social game, greet, call, and show off).
3. *Joint attention* includes communicative acts that are used to direct another's attention for purposes of sharing the focus on an entity or event (e.g., comment on object or action and request information).

These categories of communicative functions vary in sociability. As indicated earlier, children with ASD in the early stages of communication and language development have been found to show limitations in the range of communicative functions expressed. Wetherby (1986) suggested that the easiest and first emerging category of functions for these children is regulating others' behavior, whereas the most difficult is referencing joint attention, presumably because of the differing social underpinnings of these abilities. Therefore, assessment should determine the sociability of communicative functions expressed.

Persons with ASD also evidence difficulty with reciprocity or the "dance" of communicative interactions. Assessment should consider the individual's ability to synchronize and regulate turn-taking interactions (Dawson & Galpert, 1986; Klinger & Dawson, 1992). The rate of initiating and responding to communication may be a useful measure of reciprocity. Additionally,

it is important to assess the individual's ability to repair communication breakdowns. That is, when an individual's attempt to communicate is unsuccessful, what strategies are used to repair? Does the individual at least repeat the communicative signal to persist in communicating, or is the individual able to modify the signal to clarify the communicative intention? Because individuals with ASD may be faced frequently with communication breakdowns, repair strategies are critical for successful communicative interactions.

Use of social–affective signals including facial expression and displays of affect, gaze behavior, vocalizations, and other behavior reflecting emotional and physiological states should be assessed. Individuals with ASD often demonstrate limited use of gaze shifts to regulate interactions, and their emotional states may be difficult to read because of a limited range of affect expression (Prizant & Wetherby, 1990).

Assessment of social relatedness is an important component of a thorough communication assessment because communicative competence will depend, to a great extent, on an individual's social knowledge and social relationships. Social relatedness may be defined as an individual's motivation to be with, to be like, to share feelings with, and to learn from others (Prizant, 1996; Prizant & Meyer, 1993). This entails knowledge of social conventions of behavior and an understanding of others' motivations and intentions. Dimensions of social relatedness that may be assessed include social orientation (i.e., interest in being with or observing others), attachment (i.e., selective orientation toward an individual who may serve as a base of security), joint reference (i.e., the ability to establish and maintain shared attention with others), imitation (i.e., the ability to repeat actions or speech of others for social ends, or to learn from others), emotional expression (i.e., the ability to express emotional states in a readable manner), empathy (i.e., the ability to understand the emotional perspective of others), and knowledge of social rules and conventions (i.e., understanding rules of social behavior in different contexts and modifying behavior accordingly) (see Prizant et al., 1997).

Language-Related Cognitive Abilities/Symbolic Representation

Communication abilities should be considered in the context of cognitive abilities, including attentional capacities, symbolic play and object use skills, and understanding of cause–effect relations (Bates, 1979). Cognitive and social skills contribute to the foundation for the emergence of symbols, which underscores the interdependence of language and play. Level of play reflects advances in cognition that may also enhance language acquisition, and participation in play activities provides a learning context for social, cognitive, and language development.

Persons with ASD have been found to have relative weaknesses in symbolic play (i.e., make-believe play in which one object is used to stand for and represent an absent object) presumably because of the greater social demands of symbolic play (Dawson & Adams, 1984; Sigman & Ungerer, 1984; Wetherby & Prutting, 1984), and in symbolic representational capacities (Frith, 1989). Relative strengths are observed in constructive play (i.e., combining objects to create a product including drawing, block construction, and puzzle assembly; Schuler, 1995). In children with ASD at preschool and early school age, it is important to assess play skills, and to compare their cognitive level of symbolic play separate from constructive play. Because participation in symbolic play diminishes during late childhood, it is not appropriate to evaluate symbolic play in adolescents and adults with ASD, even if they have cognitive limitations. It is possible to assess knowledge of object use and level of sequential organization in daily living skills, such as setting the table and doing laundry, and in recreation and leisure skills, to provide information about nonverbal mental representation.

Assessment of the Communication Environment

The assessment of an individual's communication, language, social and cognitive abilities provides information about only one aspect of the communicative interaction. It is also necessary to assess the quality of the communicative environment, or the transactional supports available (Prizant et al., 1993). Two major dimensions of the communicative environment need to be assessed: (a) opportunities for the individual to initiate and respond to communication and (b) interactional style of communicative partner(s). Considerations for assessment of each of these dimensions of the communicative environment are addressed briefly in the following section.

Opportunities for Communicating

Environments may vary a great deal in regard to the quality and quantity of opportunities for communication. It is important to ask whether situations and persons in the environment provide ample opportunities for the individual with ASD to initiate and respond to communication for a variety of communicative functions (i.e., behavior regulation, social interaction, and joint attention). That is, does the individual have the opportunity to communicate in order to get others to do things, to draw attention to self, and to direct others' attention to objects or events?

Opportunities to communicate for behavior regulation generally involve situations in which the individual needs to request assistance or objects out of reach, to make choices about desired objects or activities (e.g., food items, toys, games, or play partner), and to indicate undesired objects or activities.

Opportunities to regulate behavior should occur throughout activities, not just when materials are first presented or activities are first initiated. Evaluation of behavior regulation opportunities will provide information about the need for environmental arrangement to increase opportunities for communicating for this purpose (see Peck, 1985).

Opportunities to communicate for social interaction and joint attention are more likely to occur within playful repetitive, turn-taking interactions. Bruner (1981) suggested that joint action routines provide the optimal opportunity for communication development and provide the foundation for learning to exchange roles in conversation. A joint action routine is a repetitive, turn-taking game or activity in which there is mutual attention and participation by the child and caregiver, exchangeable roles, and predictable sequences (see McLean & Snyder-McLean, 1999; Snyder-McLean, Solomonson, McLean, & Sack, 1984). A prototypical example of a joint action routine for a young child is the game of peek-a-boo (Bruner, 1981), which caregivers may play with their child innumerable times during the first year of life. A joint action routine may include activities involving preparation of a specific endproduct (e.g., preparing food), organization around a central plot (e.g., pretend play), or cooperative turn-taking games (e.g., peek-a-boo; Snyder-McLean et al.). Both the quantity and quality of joint action routines provided on a daily basis should be evaluated.

Interaction Style of Significant Others

In considering the role of the social context on language development, it is critical to examine the effect each communicative partner has on the other in language and communication assessment (MacDonald, 1989; Prizant et al. 1997). The developmental literature has identified the following features in interaction style as having a facilitative or enhancing effect on language development (MacDonald; Yoder, Warren, McCathren, & Leew, 1998): (a) waiting for the child to initiate communication by pausing and looking expectantly, (b) recognizing the child's behavior as communication by interpreting the communicative function that it serves, and (c) responding contingently to the child's communicative behavior in a manner that is consistent with the communicative intention of the child and that matches the communicative level of the child (e.g., labeling objects child notices or commenting about objects child labels). In contrast, a directive interaction style, which may inhibit language development and may foster passivity, has the following features: (a) initiating more than half the topics, (b) using questioning for topic continuation (e.g., *What is that?*), and (c) using directives to maintain interaction (e.g., *Look at that.*).

The interaction style used by significant others (i.e., persons who interact with the individual with ASD on a regular basis, such as parents,

siblings, teachers, peers) when interacting with the individual with ASD should be identified. Mirenda and Donnellan (1986) found that, compared to a "directive" style, the use of a "facilitative" style resulted in higher rates of student-initiated interactions, question asking, and initiation of conversational topics. Facilitative strategies have also been found to increase the initiation of communication and appropriate nonverbal behavior of autistic persons with limited or no language abilities (Dawson & Adams, 1984; Peck, 1985; Tiegerman & Primavera, 1984).

In addition to identifying facilitative versus directive styles of interaction, it is critical to assess the ability of significant others to adjust their language to the developmental level of an individual with ASD during natural interactions. When interacting with developmentally younger children, adults match the complexity of their language to the level of the child. However, significant others may have great difficulty adjusting their language to that of the person with ASD because development typically is characterized by an uneven profile. Adjusting language to an appropriate level for persons who are echolalic is particularly challenging because they may produce sentences containing many words, yet be functioning at a one- or two-word expressive language stage. Using language that is beyond an individual's comprehension is likely to be confusing and frustrating for that individual, and may lead to withdrawal or problem behaviors.

Assessment Strategies

In order to gather an accurate picture of the communicative, social, and related symbolic abilities of autistic individuals, a combination of assessment strategies are recommended (Wetherby et al., 2000). Ecologically based theories of child development address the relationship between the child and his or her natural environment and, therefore, have important implications for communication and language assessment strategies. Ecologically sound assessment strategies involve assessing an individual's language in dyads or groups involving people with whom he or she has meaningful relationships (Crais, 1995). Therefore, the assessment of language, communication, and related abilities should occur in the home, the classroom, and the community involving significant others because these are the natural environments in which an individual will need to use these abilities.

A useful initial method for gathering information about an individual's communicative and symbolic behaviors is to interview significant others. The interview should include questions about and solicit examples of behaviors within the domains delineated previously. For example, questions about how the individual is able to request help, request objects out of reach, call attention to self, or direct other's attention to objects should be asked to

determine the range of communication functions (see Peck & Schuler, 1987; Schuler et al., 1997). The use of significant others as informants ensures that the assessment will address the communicative needs of the individual with ASD and of people interacting with that individual in everyday situations.

A second source of assessment information is to observe the individual in natural contexts. Observations during regularly scheduled activities provide information about that individual's communicative, social, and symbolic behavior, as well as the adequacy of the natural environment to provide opportunities that foster spontaneous communication. It is important to compare the communicative behavior of a child or adolescent with ASD while interacting with a familiar adult to that with a familiar peer. Usually a peer will be a less competent partner than an adult, and therefore communication skills may appear more limited with a peer. Based on the information obtained from the interview, a checklist or inventory of possible communicative and symbolic behaviors and the functions they serve can be developed to measure behaviors that an individual uses spontaneously in natural contexts. Checklists can be particularly useful to establish which communicative means are used to express different communicative functions across settings with various partners (see Peck & Schuler, 1987; Schuler et al., 1997).

Although observations of natural contexts provide critical information about an individual's spontaneous communicative behavior, it may be rather time consuming to wait for behaviors to occur naturally, and some of an individual's abilities or potential may not be demonstrated even during an extended observation period. A third method to supplement an observation is behavior sampling. The purpose is to collect a representative sample of behavior typical of an individual's range of functioning in a relatively short period, preferably on videotape for later analysis. Structured communicative situations may be staged to entice an individual to interact and use a variety of communicative functions (see Schuler et al., 1997; Wetherby & Prizant, 1989, 1993). Opportunities can also be set up for the use of toys or objects instrumentally and symbolically to evaluate an individual's level of symbolic representation. In sampling spontaneous behavior, we have found that it is critical not only to provide the opportunity to initiate behavior but also to wait and look expectantly at the individual.

Assessment should be done on an ongoing basis over an extended period, not solely at one point in time. This is especially pertinent when assessing unconventional and primitive communicative acts. Furthermore, to assure representativeness, the behaviors of concern should be examined in different environments with a variety of interactants. Thus, assessment should be considered an exploratory process that is ongoing rather than episodic. Assessment of communication and related symbolic abilities, as outlined, provides a profile of an individual's strengths and needs in communication, social relatedness, and symbolic capacity, as well as information about the

interaction style of significant others and adequacy of natural environments to provide opportunities for communicating. These assessment findings provide the basis from which to derive intervention goals.

CONSIDERATIONS FOR SELECTING A COMMUNICATION AND LANGUAGE SYSTEM

Decision making for selection of a communication and/or language system should be based on an individual's social, communicative, cognitive, and motoric abilities. Table 10.2 lists specific questions that should be considered about an individual's abilities and limitations in order to develop the most optimal system or systems for communicating. First consideration needs to be given to whether an individual has the communicative abilities to support a language system, as identified under requirements for communication in Table 10.2. For individuals who do not yet have the potential for language or speech, as identified in Table 10.2, emphasis should be placed on developing a nonlanguage (i.e., nonsymbolic) communication system (see Beukelman & Mirenda, 1998, and Mirenda & Erickson, 2000,

TABLE 10.2
Questions to Consider in the Selection of a Communication and Language System

Requirements for Intention Communication
• Does the social environment provide opportunities for the individual to communicate for a variety of reasons?
• Does the individual use communicative signals (vocal or gestural) intentionally for one or more functions (i.e., behavior regulation, social interaction, and joint attention)?
• Does the individual demonstrate repair strategies when communicative intentions are not understood?
• Is the individual's current communication system (combination of nonverbal and vocal or verbal communication) readable to familiar people?
Requirements for Language
• Does the individual demonstrate the nonverbal and verbal (e.g., spoken, written, and signed) symbolic capacity for a language system?
Requirements for Speech
• Does the individual use differentiated vocalizations intentionally to communicate?
• Does the individual demonstrate the ability to imitate speech?
• Does the individual demonstrate the sensory abilities to comprehend speech?
• Does the individual demonstrate the motor abilities to produce speech (consider oral reflexes, breath support, control of phonation, differentiation and independent muscular control of jaw, lips, and tongue)?
• Does the individual demonstrate motivation and interest in speech?
• Does the individual's age and educational history indicate a good prognosis for speech?

Note: Adapted from Mirenda and Schuler (1989) and Wetherby and Hayden (1990).

for further discussion). Options include using natural gestures (e.g., giving, pushing away, manipulating others' hands) or real objects to communicate. Both of these systems can be graded in sophistication. Natural gestures can progress to indicative (e.g., pointing) and depictive (i.e., pantomimes) gestures, which are foundations for the development of language, spoken or signed. Using real objects can progress to using more sophisticated systems to refer to objects, including parts of objects (e.g., key to a wind-up toy), labels from objects or containers of objects (e.g., label from a box of raisins), or pictures of objects. These systems can lead to the development of a picture or tangible symbol system laying the foundation for written or other language systems. Because persons with ASD show a proclivity to use contact gestures, they may benefit from using a giving gesture to make choices or indicate a selection for an array of objects or pictures, rather than pointing. The Picture Exchange Communication System (PECS; Bondy & Frost, 1994) is an example of a program that uses giving or the exchange of pictures for the desired object which has been successful with children with ASD.

For individuals who communicate spontaneously and have the symbolic capacity for a language system, as identified in Table 10.2, consideration needs to be given to whether speech is a viable immediate goal. For individuals who demonstrate most or all of the abilities listed in Table 10.2 under requirements for speech, spoken language would be the system of choice because it is completely portable and universal. However, for individuals who do not demonstrate the abilities required for speech but have the symbolic capacity for language, there are many choices of nonspeech language systems varying in complexity. Nonspeech gestural language system options include sign language. Iconic signs (i.e., signs that resemble the objects and actions that they represent, such as the sign for *eat* or *tree*) may be chosen initially to minimize symbolic demands, but can only represent concrete objects or events. Nonspeech visual language system options include, from the simplest to the most complex, color photographs, black-and-white photographs, miniature objects, black-and-white line drawings, picture symbols, and written words (Beukelman & Mirenda, 1992; Mirenda & Erickson, 2000). These symbols can be represented on communication boards, communication books, or electronic communication devices.

In making decisions about communication and/or language systems for individuals with ASD, it is critical to keep in mind that any language system is a sophisticated tool for communicating. An individual needs to have the communicative competence and a supportive environment to use a language system. Decisions about the selection of a system should not be viewed as permanent but rather as a developing process. Selection of more than one system is preferable to develop a repertoire of communicative means that an individual can use to initiate communicative interactions and to repair communicative breakdowns. One system may be developed as a primary means of communicating (e.g., speech or signs) and a different system may

be used to repair communicative breakdowns (e.g., natural gestures, picture system). Emphasis should be placed on the flexible and creative use of language or nonlanguage systems for communication.

INTERVENTION GUIDELINES

Although there is consensus on the importance of enhancing social and communication abilities for children with ASD, intervention approaches vary greatly and even appear diametrically opposed in regard to specific approaches advocated. In order to examine the critical elements of treatment programs that impact on the social and communication skills of children with ASD, we have found it useful to characterize the active ingredients of treatment approaches along a continuum. This continuum ranges from traditional discrete trial to more contemporary behavioral approaches that utilize naturalistic language teaching techniques to developmentally oriented approaches (Anderson & Romanczyk, 1999; Prizant & Rubin, 1999; Prizant & Wetherby, 1998).

The earliest research efforts at teaching speech and language to children with ASD used massed discrete trial methods to teach verbal behavior. Lovaas (1977, 1981) provided the most detailed account of the procedures for language training using discrete trial approaches. Outcomes of discrete trial approaches have included improvements in IQ and improvements in communication domains of broader measures, such as the Vineland Adaptive Behavior Scales (McEachin et al., 1993). A major limitation of a discrete trial approach on language acquisition is the lack of spontaneity and generalization. Lovaas (1977) stated that "the training regime . . . its use of 'unnatural' reinforcers, and the like may have been responsible for producing the very situation-specific, restricted verbal output which we observed in many of our children" (p. 170). In a review of research on discrete trial approaches, it was noted by Koegel (1995) that "not only did language fail to be exhibited or generalize to other environments, but most behaviors taught in this highly controlled environment also failed to generalize" (p. 23).

There is now a large body of empirical support for more contemporary behavioral approaches using naturalistic teaching methods that demonstrate efficacy for teaching not only speech and language but also communication. Some examples of naturalistic behavioral approaches include natural language paradigm (Koegel, O'Dell, & Koegel, 1987), incidental teaching (Hart, 1985; McGee, Krantz, & McClanahan, 1985; McGee, Morrier, & Daly, 1999), time delay and milieu intervention (Charlop, Schreibman, & Thibodeau, 1985; Charlop & Trasowech, 1991; Hwang & Hughes, 2000; Kaiser, 1993; Kaiser, Yoder, & Keetz, 1992), and pivotal response training (Koegel, 1995; Koegel, Camarata, Koegel, Ben-Tall, & Smith, 1998). These approaches use systematic teaching trials that have the following common

active ingredients: (a) initiated by the child and focusing on the child's interest, (b) interspersed and embedded in the natural environment, and (c) use of natural reinforcers that follow what the child is trying to communicate. There are only a few studies, all using single-subject design, that have compared traditional discrete trial with naturalistic behavioral approaches. These studies have reported that naturalistic approaches are more effective at leading to generalization of language gains to natural contexts (Koegel et al., 1998; Koegel, Koegel, & Surratt, 1992; McGee et al., 1985).

A number of intervention approaches based on a developmental framework are described in the literature (e.g., Greenspan & Wieder, 1997; Klinger & Dawson, 1992; Prizant et al., 2003; Prizant & Wetherby, 1998; Wetherby et al., 2000). A feature of developmental approaches is that they are child-centered, with individualized goals based on a child's developmental profile of strengths and needs, as well as on motivations. Learning environments are arranged to provide opportunities for communication with the child initiating the interaction or activity routine, and the teacher following the child's lead by being responsive to the child's intentions, and imitating or expanding on the child's behavior. A number of studies provide support for the efficacy of developmental strategies (Hwang & Hughes, 2000; Lewy & Dawson, 1992; Rogers & DiLalla, 1991; Rogers & Lewis, 1989; Salt et al., 2001) and there are many case studies, with Greenspan and Wieder's (1997) being the largest case review. Furthermore, developmental approaches share many common active ingredients with contemporary naturalistic behavioral approaches, which have evolved by infusing developmental principles into behavioral practice, and therefore are compatible along most dimensions (Prizant & Wetherby).

Three major research findings emerge from current empirically supported intervention strategies for children with ASD and should form the basis for decision-making in planning intervention programs (National Research Council [NRC], 2001). First, there is empirical support demonstrating the effectiveness of a range of approaches for enhancing communication skills of children with ASD along a continuum from behavioral to developmental (Dawson & Osterling, 1997; Prizant & Wetherby, 1998; Rogers, 1998). Furthermore, there are no group design studies directly comparing the effectiveness of different approaches using randomly assigned, matched control samples that are methodologically sound (Dawson & Osterling; Sheinkopf & Siegel, 1998). However, available single-subject design studies have found that naturalistic behavioral approaches are more effective than traditional discrete trial approaches at leading to generalization of language gains to natural environments (DelPrato, 2001; Koegel et al., 1992, 1998; McGee et al., 1985).

Second, intervention research is not yet available to predict which specific intervention approaches or strategies work best with children with ASD. No

one approach is equally effective for all children, and not all children in outcome studies have benefited to the same degree (see Dawson & Osterling, 1997; Prizant & Wetherby, 1998; Rogers, 1998). In order to determine whether an individual child is benefiting from a particular educational program, measurement of that child's progress using methods of single-subject research design is recommended.

Third, we need to go beyond traditional outcome measures to include "ecologically compelling child characteristics" (Shonkoff, Hauser-Cram, Krauss, & Upshur, 1988). The most common reported outcome measures in comprehensive interventions for children with ASD are changes in IQ scores and postintervention placement (NRC, 2001). These measures may not be ecologically valid, because they do not measure changes within natural environments, do not address the core deficits in ASD, and are particularly problematic for infants and toddlers. Service providers need to gather meaningful measures of a child's abilities in order to guide intervention decisions and to determine whether intervention effects are being achieved. The NRC recently recognized the need for more meaningful outcome measures in research on communication of children with ASD and recommended that measures should include (a) gains in initiation of spontaneous communication in functional activities, and (b) generalization of gains across activities, interactants, and environments. The NRC concluded that current research indicates that learning in natural environments is likely to be the most effective intervention approach to address gains in initiation and generalization for children with ASD. As we work with younger children, documenting progress for the core communication skills becomes even more essential, because these skills allow for development of the early underpinnings of later social competence so that children are able to participate more successfully in developmentally appropriate activities with caregivers and peers in a variety of contexts (Wetherby et al., 2000).

The priority on successful communicative interactions across settings and partners affects all aspects of programming, from targeting goals to designing the contexts of intervention. Following are some of the major principles that should be considered in communication programming with individuals with ASD based on empirical research and current recommended practices identified in contemporary behavioral and developmental literature.

Communication Goals Should Emphasize the *Functional Use* of Language and Communication in All Natural Settings, Not Simply Teach Speech or Language Behaviors

A first *priority* in education should be in helping individuals with ASD develop a sense of the power of communication, with verbal and nonverbal means,

not simply learn a set of verbal behaviors. Individuals need to be motivated to communicate and need to have opportunities to communicate through verbal and nonverbal means. The emphasis in communication programming should be on using language and communication spontaneously for a variety of functions. We recommend beginning with an emphasis on behavior regulation functions (i.e., requesting objects and actions, protesting) because of the minimal social demands of these functions, the immediate sense of social control they offer, and the potential for socially appropriate expression of these functions to preclude use of socially unacceptable means to protest or escape from challenging situations. Once an individual is capable of communicating to regulate others' behavior, greater emphasis should be placed on communicating for more social purposes. For both prelinguistic and verbal forms, the specific purposes targeted for an individual should be serving important communicative functions relative to daily living contexts, and frequently recurring interactions with significant persons.

Enhancing functional communication should be a priority in all settings. Developing and using language and communication skills should be an *integral* part of an individual's ongoing educational, work, and living experiences to ensure ecological soundness. Communication programming needs to occur in natural environments within the context of meaningful and purposeful activities (Prizant et al., 2003) so that generalization is not an additional or final step in learning, but rather learning is guided by natural cues from the environment (Dunst, Hamby, Trivette, Raab, & Bruder, 2000). Many opportunities for choice making and initiating communication can be provided throughout the day. The individual's attempts at communicating with socially acceptable means should be responded to contingently and consistently.

Intervention goals and contexts for communication enhancement should be selected on the basis of functional as well as developmental criteria. Functional criteria should be based on the assessment information obtained from caregivers' and professionals' knowledge of an individual's communicative needs. For example, an appropriate goal for a preverbal 3-year-old may be acquisition of communicative signals to request specific social games (e.g., chase games and peek-a-boo), which clearly would not be an appropriate goal for a preverbal 12-year-old. On the other hand, developmental considerations will have great bearing on specific communicative means targeted. In the example just given, use of natural gestures or a picture communication board may be an appropriate goal for the 3-year-old or the 12-year-old, who both may be at similar developmental expressive and receptive levels, as long as goals address communicative needs in daily life routines. Without careful attention to developmental issues, communication enhancement efforts can target competencies considerably above or below an individual's capabilities.

Environmental Arrangement Should Be the Primary Teaching Strategy to Increase the Initiation of Communication

Both developmental and contemporary behavioral literature has emphasized the importance of teaching strategies that encourage individuals with communicative impairments to initiate communication and language use. In the developmental literature, the pragmatics movement has led to strategies that *follow the child's lead* to develop communication and conversational abilities (MacDonald & Carroll, 1992; Yoder et al., 1998). The developmental literature emphasizes the importance of caregiver responsivity to enhance communication and language and shifting the balance of power or control to the child (see MacDonald, 1989; Prizant & Wetherby, 1998). If there is not a balance of power or shared control in interactions with a child, the child may become a passive partner or use aggression to claim power (MacDonald).

The contemporary behavioral literature has described "incidental language teaching" as a method of achieving a more naturalistic approach to language training. In contrast to a discrete trial format in which the trainer controls the interaction, an incidental teaching episode is initiated by the child. The adult waits for a child to initiate a communicative behavior (i.e., gesture, vocalization), focuses attention on the child and the child's topic, asks for a language elaboration or models a verbal response for the child to imitate, and then indicates the correctness of the child's language or gives the child what is asked for. Incidental teaching has been found to enhance generalization in teaching language to children with severe disabilities, including ASD (see Hart, 1985, and Kaiser, 1993, for reviews).

Numerous strategies are described in the literature to design the environment to encourage the initiation of communication (Prizant & Wetherby, 1993). The developmental literature has emphasized the importance of "engineering" the environment to provide opportunities and reasons for the child to initiate communication. The behavioral literature has described specific strategies to occasion language use, such as to delay at critical moments in natural routines and to interrupt chains of behavior by removing an object needed to complete the child (Kaiser, 1993; Rowland & Schweigert, 1993). By making the initiation of communication a priority, natural opportunities for communicating can be capitalized on in all settings.

Environmental Supports Should Be Used to Promote Active and Independent Participation in Activities

Students with ASD often do not know how to participate in social activities, and so, in unstructured learning environments, they may avoid social

engagement, wander aimlessly, or behave inappropriately. Consistency and predictability in learning activities are essential for the student with ASD; the issues of motivation and independence also must be addressed. Environmental supports are strategies that make the environment more predictable so an individual with ASD can function more actively and independently (Dalrymple, 1995). Two types of environmental supports, event structure and visual supports, are presented in the following sections because they can be effective in enhancing communication and language.

An individual's day can be conceptualized as a series of activities from getting dressed in the morning to getting ready for bed at night. Familiarity with the *event structure* of an activity can enhance an individual's knowledge of how to participate in the activity and promote interaction during the activity (Prizant & Wetherby, 1993; Snyder-McLean et al., 1984; Wetherby et al., 1997). Each activity should be defined with a clearly marked opening event (e.g., check picture schedule and gather needed materials), way to participate (e.g., use materials), and closing event (e.g., put materials away). Each activity should consist of a sequence of steps that is logical and predictable to the individual with ASD using clearly marked turn-taking in which the individual can anticipate. A limited number of clearly delineated roles that are exchangeable and that require cooperation should be used to enhance communicative interactions. Predictable routines or planned activity routines (Prizant, Wetherby, Rubin, Rydell, & Laurent, in press) should be used to help an individual anticipate the sequence of events and know how to participate in the activity. The physical space and schedule or the classroom, workroom, or home should be designed to promote smooth transitions between activities and foster a sense of the daily routine. Routines can be developed to mark the opening and closing of each activity (e.g., take materials out and put materials away), to establish daily schedules (e.g., school routines for morning circle; centers; snack, lunch, and home routines for getting ready for school; after-school activities; dinner; and bedtime).

Visual supports can be used to assist a child in initiating participation within an activity. Visual supports are not simply prompts that are to be faded. Rather, they are aids that an individual with ASD can use independently in the long term, just as most professionals use a daily planner to schedule appointments. Visual supports capitalize on strengths in visual-spatial skills that are developmental strengths for most persons with ASD. One type of visual support is a picture schedule that can be used to organize sequences of time for part of a day, week, month, or year. If needed, picture (or object) schedules can be developed for portions of a day to help an individual transition across activities. Another type of visual support is a picture (or object) choice board to help a child initiate making choices in each activity. It is also important to develop clear, simple ways to indicate the many meanings

of *no* (e.g., I don't want that; I don't want to do that; I need help doing that; I need a break from that), and visual supports can assist in indicating *no*. In addition to increasing the initiation of communication, visual supports can help an individual anticipate changes in routine and ultimately enhance flexibility (see Dalrymple, 1995).

The Management of Problem *Behaviors* Should Be Fully Integrated With Communication Programming

Positive and nonaversive approaches to the management of problem behaviors are becoming widely accepted as recommended practice for individuals with severe disabilities (see Horner et al., 1990). The expanded use of applied behavior analysis, improved technology of *functional analysis* of problem behaviors, and increased awareness of developmental constructs such as emotional regulation has led to a variety of alternatives to the use of aversive procedures. These alternatives entail positive ways to support individuals who demonstrate problem behavior (see Carr et al., 1994; Dunlap & Kern, 1993; Fox et al., 2000; Horner, Albin, Sprague, & Todd, 2000; Prizant, Wetherby, Rubin, Rydell, & Laurent, 2003, in press). One of the most effective interventions derived from a functional assessment has been to teach *functional equivalents* of the problem behaviors (Carr & Durand, 1985; Horner et al., 1990). For example, for behaviors that are determined to serve a *communicative function* (e.g., to request an object, to request assistance, to express frustration or boredom, to seek attention), teaching appropriate communicative means to express the function(s) served by the problem behaviors has been associated with a reduction in the problem behavior.

In determining the success of any intervention, it is essential to consider whether the intervention has resulted in not only measurable changes but also meaningful outcomes. Meyer and Evans (1993) advocate that a meaningful outcome is a significant change in the individual's lifestyle and human condition. Communication programming should impact on the individual's lifestyle by enhancing meaningful progress in communication abilities that increases access to a variety of people, places, and events. Ultimately, it is the individual's competence in social interaction and capacity to cope with stress using flexible communicative strategies that will determine the level of independence that can be achieved in adulthood.

Peer-Mediated Learning Is an Essential Component of Education

Interacting with peers may be particularly challenging for students with ASD and needs to be addressed in education. The student with ASD should not be

the sole focus of education goals. Goals should be targeted to teach peers to interact more effectively with the student with ASD. Goals for peers need to include learning to wait for a child with ASD to initiate communication, to offer bids for social interaction, to read the communicative attempts of the student with ASD, and to respond in a manner that will encourage continued interaction.

Peer relationships can be fostered by teaching peers how to interact more effectively with a person with ASD. It is important to be aware that directing communication to other children may place great social demands on an individual with ASD, and therefore, in developing peer-directed communication, other social demands should be minimized. For example, for a young child with ASD, communication with peers can be enhanced initially for behavior regulation functions during constructive play activities because of the relatively minimal social demands of these behaviors. Relatively simpler communicative means may be acceptable when directed toward peers.

There has been a general movement over the past 2 decades toward providing services for individuals with severe disabilities, including ASD, in inclusive educational and work settings. Inclusive education is mandated by the Individuals with Disabilities Education Act (IDEA) and is considered recommended practice because it reflects principles of normalization. For a child with ASD, inclusion provides opportunities to interact with typical peers who can provide appropriate models and be responsive partners when appropriate support is provided (Goldstein & Kaczmarek, 1992; Wolfberg & Schuler, 1993). Research has demonstrated that physical integration which places students who have disabilities with typical or regular education students, does not ensure social integration, particularly for children with moderate to severe disabilities (Strain & Kohler, 1998; Strain, McGee, & Kohler, 2001). Therefore, it is essential to provide adequate adaptations and support to mediate peer interactions.

The movement toward inclusive education parallels the movement toward positive approaches to support prosocial behavior and to preclude problem behavior. Approaches to discipline must be considered from the perspective of what is acceptable to the social community so that practices can be administered in inclusive settings without stigmatizing an individual. Community- and culturally referenced behavioral support should lead to changes that impact on the individual's access to community settings, opportunities for social interaction, and choices of activities to participate in (Burack et al., 1997; Horner et al., 1990). Ideally, communication intervention should enhance communication so that greater access is provided to a variety of people, places, and events, thereby enhancing the quality of life of individuals with disabilities.

The Individual's Level of Emotional Regulation and Its Effect on Communication and Social Interactions Needs to Be Considered

An area of increasing interest to educators and clinicians is the relationship between emotional regulation and communicative competence. In reference to typically developing children, Tronick (1989) has emphasized the importance of infants' development of self- and mutual-regulatory capacities to regulate emotional arousal in potentially overstimulating and anxiety-arousing situations. Dawson and Lewy (1989) proposed that problems in *modulation of arousal* in ASD detrimentally influence attentional capacities and may ultimately account for limitations in social interaction and socioemotional development. More specific to communication, a number of researchers have discussed problem behaviors of persons with ASD in reference to the use of unconventional communicative means (Carr & Durand, 1985; Carr et al., 1994; Wetherby et al., 1997). Socially unacceptable means to communicate may be used to exert social control during states of high negative arousal. Furthermore, the inability to apply *self-regulatory strategies* to control arousal may interfere directly with social and nonsocial learning (Prizant et al., 2000; in press; Prizant, Wetherby, Rubin, & Laurent, 2003).

In planning intervention approaches, the issue of emotional regulation and its effect on communication and social participation should be addressed. First, individuals should have as a primary intervention goal the acquisition of socially acceptable means to protest or reject (Prizant & Wetherby, 1993). It has been hypothesized that such communicative skills may serve to preclude or mitigate the development of problem behaviors (Carr & Durand, 1986; Prizant & Wetherby, 1993). Second, for situations known to be stressful or anxiety arousing for an individual, strategies that the individual can ultimately use independently should be developed; for example, the use of visual supports, such as picture stimuli or picture schedules, to prepare individuals for stressful situations (Dalrymple, 1995; Prizant, Wetherby, Rubin, Rydell, et al., 2003), relaxation procedures (Cautela & Groden, 1981), or other calming or organizing activities may be implemented to help reduce arousal. Finally, educators and clinicians must be prepared to identify situations when communication may not be a successful means to support emotional regulation, and when humane and respectful strategies may be applied to assure the safety of the individual and of others in the environment. It is our belief, however, that when language and communicative interactions are adapted to an appropriate level for an individual, when environments and activities are structured in a predictable and understandable manner, and when opportunities for decision making and social control are provided, problem behavior due to negative emotional arousal can be minimized.

Prizant and colleagues (Prizant et al., 2000; Prizant, Wetherby, Rubin, & Laurent, 2003; Prizant, Wetherby, Rubin, Rydell, et al., 2003, in press) have developed the SCERTS intervention model, which incorporates these principles and blends contemporary behavioral and developmental approaches. The SCERTS model prioritizes **S**ocial **C**ommunication, **E**motion **R**egulation, and **T**ransactional **S**upport as the primary developmental dimensions that must be addressed in a comprehensive program designed to support the development of young children with ASD and their families. The SCERTS model has been derived from a theoretical as well as an evidence-based foundation and addresses core challenges of children with ASD as they relate to social-communication, emotion regulation, and transactional support. The SCERTS model also is consistent with empirically supported interventions and it reflects current and emerging "recommended practices" (NRC, 2001).

The SCERTS model was developed to address the critical need for professionals to explicitly identify the developmental foundations of a comprehensive intervention model for children with ASD, as well as intervention priorities based on our most current understanding of ASD as a developmental disability. Assessment and intervention approaches for a range of social communication, socioemotional, and related abilities are addressed in the model. These include the development of preverbal and verbal communicative means, functions of communication, reciprocity, social-affective signaling, and emotional regulatory strategies. Transactional supports for communication and socioemotional development, including supports for learning, as well as approaches to enhance the development of relationships with caregivers and peers, are also addressed as core components of the model.

CASE EXAMPLES

Three case examples of individuals with ASD were selected for presentation to illustrate how information gained from assessment of communication and related abilities can be used for intervention planning. These examples are used to characterize the heterogeneity of communication abilities in the population of ASD and to consider needs of individuals at different ages from early childhood to adulthood. The SCERTS model is used as the framework for planning intervention.

Case Example 1

Jamie is a 4½-year-old boy with ASD. He lives at home with both parents and has attended a self-contained preschool class for children with developmental and behavioral disabilities at a regular elementary school

for the past 6 months. He uses echolalia and some single words to request and protest objects and actions. He rarely coordinates eye gaze with his verbal or gestural communication or with positive affect. He has recently begun to use echolalia to greet and call, to describe pictures in a book, and to refer to events that he experiences. Jamie is a child who produces "sentences," which are actually memorized units or "gestalt language forms," but he actually is functioning at a *first-word* level in his spontaneous communication. The phrases he produces function as single words (e.g., "let me taste your wares," which was from a nursery rhyme and was used to protest: "open the door" was used to request help). He has a repertoire of fewer than 20 different spontaneous words and phrases used referentially. He only follows instructions with gestural or picture cues. He has very limited symbolic play abilities but has strengths in constructive play (e.g., block building, puzzles, and nesting cups) and gross motor activities. He has difficulty regulating his emotional state when his communicative attempts are not understood and he will display problem behaviors including aggression, screaming, and mild self-injury, which appear to serve a protest function. Jamie displays very limited ability to interact with peers and to participate in group activities in the classroom, but he is beginning to observe peers from a distance and play with them on the playground.

An immediate need for Jamie is to identify an inclusive school setting and other opportunities for regular social interactions with typical peers to provide models of appropriate language, play, and social behavior, and opportunities for successful interactions. Using the SCERTS model, priority goals in social communication, emotional regulation, and transactional support are targeted. Priority goals for social communication include increasing the use of gaze with communication and positive affect; expanding the range of communicative functions; developing repair strategies; supporting his progression through echolalia stages to more flexible, creative language; and developing symbolic play. Priority goals for emotional regulation include replacing problem behaviors with words and gestures to express these functions, regulating his emotional state during social interactions, and decreasing the amount of time to recover from being upset. Priority goals for transactional supports include having adult and peer partners model appropriate communication, language, play, emotional expressions, and behavior; foster initiation; respond to Jamie's appropriate communication; and use visual supports to structure activities and foster peer interaction. If Jamie makes progress on these goals in an inclusive setting, it is likely that he would enter regular kindergarten next year. In the home setting, Jamie's parents need assistance in learning transactional supports including how to adjust their language to his level, to respond to appropriate communicative means to replace his problem behaviors, and to provide appropriate language models to break down his echolalia and develop creative language.

Case Example 2

David is a 10-year-old boy with ASD and a moderate degree of cognitive impairment. He is living at home with both parents and has been attending a self-contained class for children with developmental disabilities since the age of 5. He communicates only to regulate the behavior of others (i.e., to request and protest actions and objects). His means of communicating include vocalizations, gestures, and, on occasion, self-injury and tantrums. His parents reported that he requests objects or assistance by leading them by the hand to the desired source. He also shakes his head or pushes an object away to indicate rejection. Traditional behavioral approaches (i.e., discrete trial training in adult-directed activities) have been used in his classroom in attempts to teach speech, sign language, total communication, and written words, with minimal success in supporting spontaneous and functional use of any of these communication systems. He does not produce any spoken words and his repertoire of conventional signs used spontaneously consists of nut, apple, orange, cracker, drink, shoe, car, book, and ball. However, he uses only the signs for book and ball referentially (i.e., to request these and only these specific objects). In requesting other objects, he typically cycles through several of the signs in his repertoire in an apparent effort to guess the name of the desired object. His expressive language level is best characterized as emerging *first words*, rather than as true *first words*. If he is not able to use the correct sign to make a choice, he usually is able to repair by manipulating another's hand to indicate what he wants. David is not able to comprehend language without nonverbal cues. David has strengths in nonverbal symbolic abilities as evidenced by his ability to draw pictures and to play video games. David rarely initiates or responds to bids for interaction with peers and does not engage productively in activities without adult direction.

Immediate needs for David in social communication include developing the use of a symbolic system for communicating. David has the communicative foundation and nonverbal symbolic capacity to learn a language system. Because he initiates communication with natural gestures and he has not made progress on spoken or signed words, it is recommended that picture symbols be considered as a language system at this point in time. Additional social communication needs include expanding the range of communicative functions using natural gestures. Needs in emotional regulation include increasing his initiations and responses to social interaction both with adults and peers and with increasing the time that he is engaged productively during learning activities. Needs in transactional support include offering choices and waiting to encourage initiation, recognizing and responding to David's appropriate communication, using visual supports to structure activities and active engagement, increasing opportunities to

interact with peers, and expanding education to community-based settings. His parents are effective at reading his communicative signals and responding contingently, but need assistance in using transactional supports in the home environment to provide more opportunities for David to initiate communication and build a language system.

Case Example 3

Nona is a 20-year-old woman with ASD. She lives at home with both parents and has been attending a self-contained class in a center school for students with developmental disabilities. She uses both echolalia and creative speech to request objects and actions, to protest, greet, comment, and to describe events that she has experienced. Nona uses over 100 different object names referentially, some in the phrase "want some more____please" to request these items. These phrases are equivalent to two-word combinations for her. She also uses a number of delayed echolalic utterances, such as "stop doing that" to protest and "time to say goodbye" to greet, which are equivalent to single words. Nona's language level is best characterized as emerging *first-word combinations.* On occasion she displays very volatile behavior related to states of emotional dysregulation, including self-injury, aggression, and destructive behavior. These behavioral outbursts occur when she is corrected for an error, her communicative attempts are not understood, or when an expected routine is violated. In her school and home setting, these behavioral outbursts are consequated by sending her to a time-out area. Nona has learned to ask for a deck of cards when she is upset to play a game of "Fish" or solitaire; dealing and handling cards has a calming effect on her. She is able to organize multiple steps in sequence for daily living activities (e.g., obtaining and sorting materials to set the table; preparing, stirring, and serving frozen juice drink; dealing cards for game of "Fish"). A relative strength for Nona is apparent in her constructive play, as demonstrated by her ability to put together a 1,000-piece jigsaw puzzle. Her parents' interaction style is characterized by frequent question-asking, particularly ones that they already know the answer to, and using language that is beyond Nona's comprehension level. They are beginning to seek residential placement in a group home setting in preparation for her transition into adulthood.

High-priority immediate needs for Nona are in emotional regulation and include replacing her problem behaviors with simple verbal means to express the function(s) served, regulating her emotional state using cognitive strategies (e.g., using deck of cards or other activities to calm herself and a picture schedule to make her day predictable), decreasing the intensity of her dysregulated state, and decreasing the amount of time to recover from

dysregulation. Additionally, social communication goals include developing repair strategies to clarify meaning, expanding her use of a variety of words to increase the informativeness of her utterances, and breaking down her echolalia into meaningful units. Because her language level appears much higher on the surface, it may be tempting to increase her utterance length by targeting pronouns and specific grammatical structures. However, she does not have the pragmatic and semantic language base for sentence grammar. It is unlikely that her educational setting will change in the next year. However, her parents need information that will assist them in making decisions about group home and job placements. Her parents also need assistance in transactional supports including adjusting their language to her language level, using a facilitative interaction style, as well as encouraging Nona to provide needed "information" when talking with them.

SUMMARY AND CONCLUSIONS

The communication and language impairments associated with ASD have a significant impact on the outcome of individuals with ASD and on their family. Current understandings of communication and language development in ASD suggest that difficulties acquiring conventional communicative behaviors to express intentions effectively are related to underlying social–cognitive and socioemotional limitations. In this chapter we identified the following factors as important for individualizing a communication program: developmental appropriateness of communication goals, the individual's chronological age, social supports available to the family, and the setting or context of communication programming.

Communication and language abilities of persons with ASD need to be examined in natural communicative interactions. Assessment of communication should identify the repertoire of communicative means and the level of language production and comprehension. A communication assessment should also examine the communicative functions expressed as well as the range of behaviors used for communication, the abilities to repair communication breakdowns, the use of social–affective signals, and aspects of social relatedness. Communication abilities should be considered in the context of cognitive abilities and symbolic capacity. Additionally, a communication assessment should also address the communication environment by examining opportunities for communicating and the interaction style of significant others. Because formal assessment tools do not assess these areas, a variety of informal assessment strategies were recommended. Guidelines for decision making for the selection of a communication and language system should be based on the individual's social, communicative, cognitive, and motor abilities.

Advances in our understanding of ASD indicate that core deficits in joint attention, conventional and symbolic aspects of communication, symbolic play, and shared affect are associated with communication and language abilities. The effectiveness of communication intervention programs needs to be documented relative to these core deficits. Major principles that need to be considered in communication programming with autistic persons should be based on "current recommended practices" identified in the contemporary literature discussed in this chapter. That is, communication and language intervention programs for individuals with ASD should target goals focusing on communicative competence in natural language learning environments with the emphasis on acquisition of functional skills that support successful communicative interactions.

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Chapter 11

Structuring Behavior Management Strategies and Building Social Competence[1]

Richard Simpson
Kaye Otten
University of Kansas

INTRODUCTION

Children and youth with autism spectrum disorders (ASD) present major challenges to teachers and other caregivers. Specifically, they commonly display unique behavioral and social characteristics that need to be managed before they are able to develop essential knowledge, skills, and independent functioning abilities (Koegel & Koegel, 1995; Scheuerman & Webber, 2002). Individuals with ASD are characterized by social skill deficits, such as maintaining appropriate eye contact (Scheuermann & Webber, 2002), turn-taking while interacting with peers (Schuler & Wolfberg, 2000; Simpson, Myles, Sasso, & Kamps, 1998), responding to peer initiations (Kamps, et al., 1992; Scheuermann & Webber), and initiating and maintaining socially acceptable peer interactions (McConnell, Sisson, Cort, & Strain, 1991; Sasso, Simpson, & Novak, 1985). Children and youth with autism are also well known for their behavioral excesses, including aggression (Scheuermann & Webber), self-stimulatory behavior (Howlin & Rutter, 1987; Scheuermann & Webber), self-injurious behavior (SIB) (American Psychiatric Association [APA], 1994; Scheuermann & Webber), atypical responses to sensory stimuli (Simpson & Regan, 1986; Wing, 2001), and a variety of other aberrant

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behaviors (Bell & Stein, 1992; Wing). Few children with ASD present with all these behavioral and social deficits and excesses (e. g., relatively few individuals with ASD manifest significant SIB). Nonetheless, these challenging behaviors occur with such regularity that anyone who aspires to successfully teach, parent, or otherwise work with individuals with autism spectrum disorders requires the support of well-developed structuring and management methods.

According to the Individuals with Disabilities Education Act (IDEA), "The IEP team shall in the case of a child whose behavior impedes his or her learning or that of others, consider, when appropriate, strategies, including positive behavioral interventions, strategies and supports, to address that behavior" [20 U.S.C§1414(d)(3)(B)(I); 34C.F.R.§300.346(a)(2)(i)]. IDEA does not specifically define positive behavioral interventions and supports, commonly referred to as PBIS or PBS. However, a multiuniversity consortium that provides technical assistance related to PBIS identifies four components: (a) systems change, (b) environmental alterations, (c) skill instruction (including the student and those involved with the student), and (d) behavior consequences (Turnbull & Turnbull, 2000). PBIS is also defined by six basic characteristics: (a) views systems, environments, student's skill deficiencies, and others' skill deficiencies as interrelated components that influence the occurrence of impeding behaviors and attempts to make adjustments and accommodations in all of them; (b) creates new contacts, experiences, relationships, and skills for the student; (c) acknowledges that it can take significant investments of effort, over a long period of time, to achieve significant change within the four basic components; (d) are developed, implemented, and evaluated by a team of professionals, family members, the student, and members of the student's social and family network through a flexible, person-centered planning process in typical environments; (e) establish acceptable behavioral criteria based on the type of lifestyle that the student and the student's family desire, determining the social validity of the education and interventions that the students receives, and assessing the quality of life that the student may attain; and (f) are designed and implemented to the greatest extent possible in the general curriculum and in all other educational and life settings of the student by individual who have received some training in their use and evaluation (Turnbull & Turnbull, 2000).

This chapter has as its foundation the premise that an effective educational program for students with ASD is contingent on implementation of an appropriate management program based on the components and characteristics of PBIS. This chapter focuses on antecedent manipulation and environmental structuring; individualized management tools and strategies for children and youths with ASD including guildelines for considering

novel interventions that appear to hold good promise for the future; and generalization, maintenance, and follow-up strategies.

ANTECEDENT MANIPULATION AND ENVIRONMENTAL STRUCTURING

Various attempts to provide educational and treatment services to individuals with ASD have been reported since Kanner (1943) first identified the syndrome. Over the years, these early intervention attempts have been modified and refined so that today there are recognized effective methods for facilitating functional outcomes for people with ASD (Twachtman, 1995; Westling & Fox, 1995). Included among these recognized methods are procedures for manipulating environmental stimuli to which children and youths with ASD are exposed (Dalrymple, 1995; Scheuermann & Webber, 2002). These antecedent considerations include (a) therapeutic use of routines and schedules, (b) clear expectations and consistent consequences for behavior and classroom performance, (c) physical and environmental support, and (d) effective instructional techniques and curricula.

Therapeutic Use of Routines and Schedules

Therapeutic use of routines and schedules refers to building on the preferences for sameness and consistency common among individuals with ASD and recognizing their responsiveness to predictability and order (Scheuermann & Webber, 2002). Most children and youths are able to effectively respond to a myriad of environmental variables and to easily adapt to their ever-changing world. Students with ASD, by contrast, commonly respond to limited numbers of environmental stimuli and respond negatively to even minor environmental changes, such as the positioning of their desk, the arrangement of items on a snack table, or alterations in the sequence of daily activities. Indeed, deviations from routine or other changes of typical environmental stimuli may result in severely impairing a child's overall behavior and performance.

In keeping with this preference for sameness and consistency, a structured program for students with ASD builds on routines. For example, students are taught to follow routine procedures for exiting their school bus and entering the school building in the morning, and reversing this process in the afternoon. Obviously, it is neither possible nor desirable to script and establish a routine for every minute of a child's day. Regardless of whatever steps are taken, environmental conditions do change. Thus, children with

TABLE 11.1
Example 1: Daily Student Schedule

Donny is a 10-year-old male diagnosed with autism educated in a self-contained classroom for students with ASD who function at a variety of educational levels. Donnie has learned to read a variety of functional words and is learning to tell time. His schedule is placed in a folder each day and he crosses out activities as he completes them. Because he is learning to tell time, a picture of a clock indicating the appropriate time is placed next to each activity. His schedule is reviewed with him each morning so that any changes can be discussed and appears as follows:

Morning Routine	8:45	
Breakfast	9:00	
Hello Group	9:30	
Math	10:00	
Reading	10:45	
Gym	11:30	
Lunch	12:00	
Recess	12:30	
Work Time	1:00	
Leisure	1:30	
Language Group	2.00	
Music	2:30	
Cooking/Snack	3:00	
Good-bye Group	3:30	

Note: The clocks on the right should correlate to the time indicated on the schedule.

ASD should be systematically exposed to changes that facilitate flexibility and adaptability to the constantly changing world around them while at the same time heeding their responsiveness to routine. In this context, it is important to identify key daily routines that can start a student on a successful note and maintain positive performance, and to recognize salient environmental variables directly associated with students' functioning that may be translated into routines.

Schedules can also be used to establish routines and assist students in appropriately responding to environmental changes. Individual visual schedules are especially useful in communicating specific daily activities, reminding students of the sequence of scheduled activities, and alerting them to schedule deviations or new activities (Table 11.1, and Table 11.2).

Clear Expectations and Consistent Consequences

Providing structure also involves using clear behavior and classroom performance expectations, including close monitoring of class rules and consistent use of consequences. Children and youths with ASD are characterized by communication and often cognitive impairments, which can make it

TABLE 11.2
Example 1: Daily Student Schedule

Donna is a 13-year-old female with low-functioning autism educated in a middle school program for developmentally disabled students. She is unable to read but is able to recognize and verbally identify icons and photographs. Her schedule is in a small picture album. A picture is on each page of the album to represent each activity of the day. She assists the teacher or paraeducator with assembling the schedule each morning.

Morning Routine
- Coat and backpack
- Bathroom
- Schedule

Hello Group

Vocational Task

Gym

Lunch

Recess

Group Work Time

Leisure

Language Group

Music

Cooking/Snack

Good-bye Group

Bus

very difficult to clearly communicate desired behavior (Ogletree, Fischer, & Turowski, 1996; Simpson & Myles, 1998). Thus, an important element of classroom structure for students with ASD is to ensure that they have a clear understanding of classroom expectations and consequences. This goal may be accomplished in a variety of ways, including regularly reminding students of rules, incorporating reviews of classroom expectations and rules into classroom routines, putting expectations for classroom performance and classroom rules in visual form, rehearsing desired classroom behaviors, identifying visual and motor responses that cue students regarding unacceptable responses, and teaching students to follow scripts related to desired behavior.

Physical and Environmental Support

Physical and environmental support relates to having adequate human and nonhuman resources available to effectively manage a group of students with ASD in various settings, including special education classrooms, general education classrooms, recess, lunch, community, and so forth. The need for human resources varies with the needs of individual students. However, it is essential to have (a) teachers who are knowledgeable and skilled in working with students with ASD; (b) related services staff who are skilled in working with children and youth with ASD, including speech therapists, occupational therapists, school psychologists, and other related ancillary personnel; (c) consultants who are available to train and assist staff on an as-needed basis; and (d) suitably trained paraprofessionals. Paraprofessionals are increasingly assuming major roles in working with students with ASD in special and general education classrooms. Thus, it is essential that these individuals be well trained. At the same time, however, they must not be asked to supplant the role of professional staff.

Nonhuman resources include a classroom environment that addresses the unique needs of students with ASD. Depending on the needs and numbers of students, minimum requirements for special education classrooms include individual work, small-group, large-group, free time, vocational work, general-use, time-out or behavior-control (as needed), independent living, self-help, and toilet areas in addition to adequate storage space (Simpson & Regan, 1986).

Effective Instructional Techniques and Curricula

Effective curricula and instructional methods may not be commonly perceived as a major management tool. Nonetheless, there is overwhelming evidence that effective curriculum planning is an essential factor in managing behavior (DePape, Shores, Jack, & Denny, 1996; Dunlap, Kern, & Worcester, 2001; Scheuermann & Webber, 2002). Curriculum planning involves consideration of major domains, including social and behavioral, self-help and independent living, motor, language and communication, sensory, academic, and vocational. Educators of students with ASD commonly express concern over the challenge of selecting curricula to meet the needs of their students. One reason for this difficulty is that curricula choices for many students with ASD are less well defined than these for many other students with disabilities. Moreover, children and youths with ASD who have severe disabilities may receive little apparent benefit from instructional programs based on a district's general education curriculum. Finally, educators have yet to reach a consensus on the most effective instructional methods for students with

ASD. As a result of these factors, educators of students with ASD routinely draw from a variety of curricula and instructional methods. Individualized programs developed around the domains identified previously play a major part in effective programs for this group of students. Effective programs incorporate the basic principles of effective instruction, such as (a) ensuring that students' time on tasks is maximized, (b) students are programmed for success, (c) educational personnel are actively involved in the teaching and learning process, (d) teaching is based on direct instruction methodology, (e) educational personnel are responsive to students, and (f) teachers establish and maintain appropriately high expectations for their students. Careful attention to curricular and instructional matters is a basic structuring method, as well as an essential method for ensuring students' behavioral and social success.

MANAGEMENT TOOLS AND STRATEGIES

An underlying principle behind this section is that successful management of children and youths with ASD is a multifaceted process. Effective educational programs must adhere to a structured model (i.e., therapeutic use of routines and schedules, clear expectations and consistent consequences for behavioral and classroom performance, physical and environmental support, and effective instructional techniques and curricula). These factors not only facilitate students' learning but also reduce the probability of behavior problems. Nonetheless, even when such effective practices are in place, students with ASD periodically require additional individual management programs.

Behavioral Interventions

Individualized management programs for students with ASD based on behavioral methodology have a strong research base supporting their use. In this context, we consider behaviorally based procedures to be highly adaptive and flexible, even though they have sometimes been narrowly interpreted as exclusively meaning one-to-one discrete trial training. Intervention programs based on behavioral principles have been found effective in achieving a variety of desired social and behavioral outcomes (Groden & Baron, 1988; Koegel & Koegel, 1995; Scheuermann & Webber, 2002; Simpson & Regan, 1986). For example, they have been used to decrease aggressive behavior (Farrar-Schneider, 1994; Gardner & Cole, 1990), increase social interactions (Simpson, et al., 1998), reduce self-injurious behavior (Azrin, Besalel, Jamner, & Caputo, 1988; Iwata, Pace, Kalsher, Cowdery,

& Cataldo, 1990), reduce self-stimulatory behaviors (Epstein, Taubman, & Lovaas, 1985), and positively affect a variety of other behavioral excesses and deficits (LaVigna & Willis, 1992). Further evidence of the versatility and efficacy of these methods is that they have been successfully used by both parents and professionals in various settings with a variety of age groups (Powers, 1992; Risley, 1968; Simpson, 1996).

Based on this successful record, this section offers a behaviorally based model and procedures for developing individualized management programs for students with ASD. The model elements consist of (a) identification and measurement of individual behavior(s) for change; (b) analysis of antecedent and environmental conditions associated with the target behavior(s); (c) analysis of behavioral contingencies and functions associated with the target behavior(s); (d) selection of appropriate intervention procedures and; (e) generalization, maintenance, and follow-up activities.

Identification and Measurement of Individual Behavior(s) for Change

Identification and measurement of individual behavior(s) for change refers to identifying and defining target behaviors for modification. The intent of this effort is to define a response such that all individuals involved with the student (e.g., teacher, parent, paraprofessional) are able to reliably observe and recognize the behavior. For example, aggressive behavior might refer to screaming according to one teacher, whereas according to another it might mean self-hitting. A simple means of achieving functional definitions that facilitate interobserver reliability is to develop behavioral descriptions which include the four w's (Clark-Hall et al., 1976): (1) who the target individual is, (2) when the target behavior will be measured, (3) what the behavior is, and (4) where the behavior will be measured (Table 11.3).

Hall (1970) identified five basic observational options for accurately measuring target behaviors: (a) frequency observations, (b) duration

TABLE 11.3
Example 3: Functional Definition of Behavior

Operational Definition for Throwing: Any purposeful movement of the arm or hand by Leonard that propels an object in the classroom during any scheduled activity.	
Who	Leonard
What	Purposeful movement of the arm or hand that propels an object
Where	Classroom
When	Any scheduled activity

observations, (c) interval recordings, (d) time samples, and (e) continuous observations. Use of one or more of these options has been associated with reliable measures of target behaviors (Axelrod, 1983). Because students with ASD often present with a variety of behavioral excesses and deficits, individuals who develop intervention programs must establish priority behaviors for change. As a general rule, programs should be designed to ameliorate severe behavioral excesses before attempts are made to focus on deficit areas. This recommendation is based on the assumption that children and youths who display severe behavioral excesses should have their challenges be priority considerations. This does not mean that all behavioral excesses should be dealt with before deficit areas are addressed, but rather that students involved in social intervention and other behavioral deficit programs must demonstrate basic requisite behaviors before such programs can be effective. Selection of behaviors for change is based on students' records; interviews with teachers, other professionals, and parents; behavioral observations; formal and informal assessments; and analysis of students' current individualized education programs.

Analysis of Antecedent and Environmental Conditions

Analysis of antecedent and environmental conditions associated with target behaviors refers to determining whether or not a behavior occurs primarily in certain settings or under particular conditions (e.g., during independent work following morning recess) or whether it is pervasive across environments, people, and situations. Identification of settings and circumstances associated with a particular behavior also includes an evaluation of individuals who are connected with particular situations. In this regard, Bersoff and Grieger (1971) noted that "obtaining knowledge about environments and situations in which behavior appears is a necessity" (p. 487). Similarly, Bandura (1969) observed that, "under naturalistic conditions behavior is generally regulated by the characteristics of persons toward whom responses are directed, the social setting, temporal factors, and hosts of verbal and symbolic cues that signify predictable response consequences" (p. 25). Accordingly, clarifying variables and conditions connected with the target behavior is a basic step in the process of identifying factors connected to a target behavior and thus in developing an appropriate behavior intervention program (Fox, Dunlap, & Buschbaber, 2001)

Analysis of Behavioral Contingencies and Functions

The importance of analyzing behavioral contingencies and functions associated with target behaviors has been increasingly recognized in recent years (Davis & Fox, 2001; Fox, Dunlap, & Buschbaber, 2000). Attempts are made to identify and evaluate antecedent and consequent events, stimuli,

and patterns associated with target behaviors. However, it is clear that it is unrealistic to expect to gain a comprehensive understanding of all the variables that influence a child's behavior. Accordingly, efforts in this area should be designed to identify major factors associated with particular behaviors of concern. For example, Sasso and Reimers (1988) identified five basic functional analysis conditions for clinical and classroom analysis: "alone, social disapproval, tangible, toy play, and demand" (p. 3). Each of these conditions was translated into situations into which students were placed for observation and analysis. For example, alone involves observing a child in a setting devoid of people, toys, or other stimuli, as an environment supportive of self-stimulation. Sasso and Reimers recommended observing students under each of these five conditions, and based on their responses, developed appropriate intervention programs. For example, the demand condition (i.e., adults present structured tasks for children to complete) permits analysis of whether a response is being used by a student to escape or avoid certain instructional demands.

An informal direct observation format is recommended when conducting a functional analysis. Informal observations and recordings of interactions between students and teachers in various settings related to occurrence and nonoccurrence of reported management problems offer an efficient and effective means of assessing behavioral functions. For example, the analysis form shown in Table 11.4 was used to understand the behaviors of an adolescent with Asperger syndrome in special and general education settings. Although capable of functioning at grade level, this student was reported to experience behavioral problems, especially in general education settings. Accordingly, two morning observations were made: one of them in a special education setting where the student was involved in an independent academic activity. The other observation took place in a general education social science class.

As revealed, the observations involved analyzing the student's interactions and responses relative to various class assignments, as well as the ensuing consequences and responses. That is, the consequences were the reactions of the student's teachers to his various behaviors, whereas the response was the student's reaction to his teachers' consequences. In the example shown in Table 11.4 from the special education setting, the student was reluctant to work on an assigned task. However, through the use of prompts, physical proximity, academic hurdle help, and social reinforcement, his teacher was able to obtain marginal attention. The subject's behavior was similar in the general education classroom. As illustrated in the analysis, the general education teacher was far less tolerant than the special education teacher and removed the student from the class after approximately 15 minutes.

Based on this analysis, hypotheses were formed and tested. Ultimately, it was determined that the curriculum, instructional method, and an attempt to avoid particular situations were salient factors. Accordingly, an

TABLE 11.4
Example 4: Informal Functional Analysis

Time	*Setting*	*Task*	*Behavior, Consequence, and Response Analysis*
8:15–9:08 a.m.	Special education resource room	Independent academic task	B: Failure to start assignment C: Verbal prompt R: Brief on-task behavior C: Teacher proximity R: Brief on-task behavior B: Complaint regarding assignment C: Teacher discusses assignment with student. Teacher assists student in structuring task. R: Brief work on task C: Teacher reminds student of classroom rules regarding work assignments R: Student works sporadically the remainder of the class session C: Student reinforced for working
9:15–10:08 a.m.	General education (social studies)	Lecture & full class discussion	B: Failure to attend C: Verbal reprimand R: Brief on-task behavior; head on desk C: Teacher warning to attend R: Brief attention; head on desk C: Student is sent to the office

intervention plan useful for both special education and regular education was developed and implemented. As with virtually every functional analysis effort, this process rarely leads to initial conclusive results. Nonetheless, a functional analysis does offer an efficient and potentially effective tool for gaining insight regarding factors associated with students' behaviors and a means for better understanding the function and outcome of individuals' behaviors.

Selection of Appropriate Intervention Procedures

Selection of appropriate intervention procedures refers to the use of consequences and antecedent manipulation to modify behaviors targeted for change. These interventions fall into the categories of antecedent

interventions, reinforcement programs, extinction procedures, behavior reduction methods, and cognitively based methods. Thus, based on an analysis of behaviors targeted for change, programs involving these intervention options are developed, implemented, and evaluated. Each of these interventions is described in the following sections, along with program examples.

Reinforcement. Intervention programs based on reinforcement involve following desired behaviors with positive or desired consequences. Because positive or desired consequences are highly individual, they are determined by their capacity to increase a behavior. That is, reinforcers increase the future probability of a behavior. Changes may take place in two ways. First, behaviors that are followed by reinforcing consequences are usually repeated. For example, a student with ASD who increases his or her work completion as a result of receiving contingent free time can be assumed to be positively reinforced. Second, a response can be increased by removing an unpleasant stimulus (negative reinforcement). For example, an adolescent may be permitted to miss a vocational training session if his or her social behavior meets specified criteria. If this program leads to a significant improvement in behavior, it can be inferred that the contingent removal of the vocational training activity is reinforcing for the student. Although negative reinforcers may result in desired behavioral changes, they are often less desirable than positive reinforcement procedures that often achieve the same goals as negative reinforcement while offering obvious interpersonal advantages.

A number of positive reinforcement programs have proven effective with children and youths with ASD. Several of them are discussed here, including (a) tangible and edible reinforcers, (b) contingent activities, (c) social reinforcers, and (d) token economy systems.

Tangible and Edible Reinforcers. Tangible and edible reinforcers appear to be most appropriate for use in obtaining initial responses from young and low-functioning children. It is also recommended that such reinforcers be paired with social reinforcement. Edibles and other tangible reinforcers have been used to stimulate a variety of responses, including language, compliance, and completion of independent tasks.

Although they are powerful reinforcers, edibles and tangibles are most effectively used with several basic guidelines in mind. First, care should be taken not to satiate a child. Second, it is important to monitor intake to avoid possible food allergies. Third, it is important to remember that a variety of foods and tangibles can be used as reinforcers. Thus, even though raisins, dry cereal, and so forth, tend to be most commonly used, meals at restaurants may also be used as primary reinforcers. Finally, it should be kept in mind that the single most important consideration in selecting food or tangible reinforcers is the student's preference (Table 11.5).

TABLE 11.5
Example 5: Reinforcement Program Using Edibles

Michael is a kindergarten student diagnosed with low-functioning autism educated in a developmental kindergarten classroom. Michael is content to sit in the corner of the classroom and rock or play with a piece of string, his most preferred activity. However, he is also motivated by food and comes willingly to lunch, cooking, or snack groups. When he is asked to come to his morning group, he protests loudly by screaming and crying. When staff members approach him during this time he will attempt to hit, bit, kick, and scratch them.

A program was implemented to encourage Michael to participate in this morning group. When a single request was made for Michael to join the group, he refused in his usual manner. When all of the other children were settled, a timer was set for 1 minute. When the bell rang, the group stopped and each child was rewarded with a raisin and verbal praise for "good sitting." When Michael saw that edibles were being given, he quickly came to the group. He was praised for "good sitting" and was given a raisin. After eating the raisin, he left the group. The timer was reset for 1 minute. When the timer bell sounded each child in the group again received a raisin. At the end of the first week, Michael's time with the morning group increased from 0% to 80%. The time between edible reinforcement was gradually increased and by the end of the first quarter, Michael was able to stay in the group for 15 to 20 minutes with only a small edible reinforcement at the end of group time.

TABLE 11.6
Example 6: Reinforcement Program Using Contingent Activity

Lisa is a 7-year-old student diagnosed with pervasive developmental disorder not otherwise specified (PDDNOS). She attends a public school, spending part of her day in a classroom for students with ASD and part of her day in a regular education second-grade classroom. She is verbal, yet much of her language is difficult to understand. She is motivated by a variety of activities, including computer time, playing with clay, listening to tapes on a cassette recorder, and reading the phone book. Because Lisa is motivated by a variety of activities, a reinforcement menu was developed for her, involving placing pictures of preferred items on a poster in her work station. A token system was implemented, requiring Lisa to earn a designated number of tokens in order to receive a choice of an activity on her reinforcement menu. Each activity she completed earned her a token, and five tokens earned her 5 minutes of time with the activity of her choice.

Contingent Activity Reinforcers. Contingent activity reinforcers involve making certain activities (e.g., game time with a peer or adult) contingent on particular types and levels of desired behavior (Myles & Simpson, 2003). For example, a student might be required to complete a prescribed amount of academic work while displaying desired social behaviors in order to acquire additional free time. Contingent activities are extremely flexible and effective and are commonly used across various educational settings, including general education classes. Thus, these methods tend to be desirable for students with ASD who are assigned to inclusionary settings (Table 11.6).

TABLE 11.7
Example 7: Reinforcement Program Using Social Reinforcers

Scott is a 14-year-old student with classic autism who attends a middle school program for youth with ASD. He has limited verbal abilities and communicates using a variety of methods, including verbalization, gestures, limited signing, and icons. Scott is affectionate and enjoys hugs. Unfortunately, this became a problem when he insisted on hugging everyone he met and hugging familiar people repeatedly throughout the day. A program was developed to teach Scott to request hugs using an icon. "Hug cards" were made on 3 × 5 index cards. Scott received five cards in the morning and he was taught to exchange a card for a hug. A social story was written to explain this program to Scott including information on who he could hug at school. When Scott attempted to hug someone he was prompted to exchange a "hug card" for the hug. If the person was not someone on his "hug list," staff directed him to reread his social story. This program was used to reinforce desired behavior and to teach Scott whom it was and was not appropriate to hug.

Social Reinforcers. Social reinforcers, a basic element of any successful management and instructional program, include a variety of positive contacts with others, such as supportive verbal and nonverbal responses made contingent on desired behavior. Selection of the most effective and appropriate methods of communicating approval depends on the results of functional analyses and students' unique social preferences. Accordingly, contrary to the widespread belief that individuals with ASD dislike social contact with others, verbalizations, touches, hugs, and so forth may be used to reinforce desired behavior (Table 11.7)

Token Economy Systems. Token economy systems are based on exchanging tangible, conditioned reinforcers (tokens) for desired items. Thus, as described in an earlier example, students earn back-up reinforcers such as poker chips, play money, and so forth, which are exchangeable for primary reinforcers. The advantages of token systems are numerous: (a) They are often able to maintain behavior at a higher level than other conditioned reinforcers such as praise, social approval, and feedback; (b) tokens bridge the delay between desired behavior and back-up reinforcement; (c) tokens can be exchanged for a variety of reinforcers, thus are less subject to satiation than other reinforcers; (d) tokens can be administered without interrupting desired target responses; (e) they allow for use of a single reinforcer with several students who might otherwise have different reinforcement preferences; (f) they permit using portions or parts of reinforcers (e.g., minutes of free time rather than requiring that a reinforcer be earned in an all-or-none fashion); (g) they typically are available in most settings; and (h) they provide a quantitative basis on which to evaluate program and student progress (Table 11.8).

TABLE 11.8
Example 8: Reinforcement Program Using a Token Economy

Eric is an 8-year-old male diagnosed with autism, educated in a self-contained classroom for students with developmental disabilities. In order to earn tokens, Eric is required to complete a variety of work tasks in his classroom. Eric uses these tokens to "purchase" reinforcing activities off a menu designed by his teacher based on his preferences with input from Eric. Eric's rate of work and amount of work completed increased dramatically over time using this token economy system.

Behavior Reduction. Behavior reduction involves using undesired consequences or withdrawing reinforcement contingent on identified unacceptable behaviors. Behavior reduction methods are recommended primarily when positive alternatives have been found to be ineffective. The rationale for conservatively using behavior reduction options is that negative consequences may inadvertently reduce desirable behaviors, and that individuals involved in dispensing them may themselves become punishers. Moreover, some students with autism have difficulty discriminating between positive and negative attention and may display maladaptive behavior to get attention, regardless of whether it is positive or negative. However, when used conservatively, appropriately, and under the correct conditions, behavior reduction methods represent a valuable intervention option.

It is recommended that behavior reduction methods be used under the following conditions: (a) when positive reinforcement methods, extinction, or both have proven unsuccessful, or when it is determined that such procedures are unacceptable; (b) when a maladaptive behavior occurs so frequently that there is an absence of incompatible behaviors to reinforce; or (c) if a maladaptive behavior is so intense that it presents a danger to the individual or others. In addition, when a behavior reduction tool is used, it is recommended that it be (a) paired with positive reinforcement for acceptable behavior, (b) systematically and consistently carried out by all individuals involved with the person, (c) promptly delivered, (d) implemented in a nonemotional and nonjudgmental fashion, and (e) paired with a verbal or motor warning. When administered prior to a behavior reduction consequence, the warning signal may become a conditioned punisher. We also recommend that when behavior reduction options are used: (a) prior written approval be obtained from parents, administrators, and other appropriate individuals; (b) a detailed description of the program be developed, including what will be done, who will do it, how long the procedure will be used before it is formally evaluated, and what kind of data will be collected for evaluating the program; and (c) the parents and family be informed frequently relative to progress. A variety of behavior reduction methods have been used with individuals with ASD, including extinction, response cost programs, time-out, overcorrection, and differential reinforcement.

Extinction. Extinction programs involve systematic cessation of previously reinforced behaviors. Accordingly, undesired behaviors are decreased or eliminated by having individuals associated with the perceived problems withhold contingent attention reinforcement. For example, a student who consistently makes loud sounds in order to secure teacher attention would be denied contingent reinforcement. The utility and effectiveness of extinction programs have been clearly established (Williams, 1959), especially when used in combination with other programs, such as differential social reinforcement. Nonetheless, use of extinction involves consideration of several potential problems. First, extinction program effectiveness is dependent on controlling the attention that is maintaining a response. Thus, extinction programs must be based both on an accurate analysis of reinforcers for a particular behavior as well as on control over these variables. That a student may be, at least partially, reinforced for an undesirable behavior by her peer group, parents, or others often makes effective use of extinction a significant challenge. Second, extinction programs that gain only partial or intermittent control over a behavior may actually make the behavior more difficult to extinguish (Skinner, 1938). Third, extinction programs often result in short-term increases in undesired behaviors or the occurrence of other more intense maladaptive responses. For example, if a nonverbal child with a propensity to scream in order to attract attention from her teacher is exposed to an extinction program, the child's initial response may be to increase her screaming in order to obtain the attention that is being denied. Some students may also occasionally turn to behaviors that are impossible to ignore. For example, a child who engages in hitting peers when ignored by his teacher when he screams would likely need an intervention program other than extinction. Finally, students whose behavior is not reinforced by attention would be unresponsive to extinction programs. In spite of their weaknesses, extinction programs are appropriate for many students with ASD (Lovaas, Freitag, Gold, & Kassorla, 1965; Simpson & Myles, 1998; Wolf, Risley, & Mees, 1964) (Table 11.9).

Response Cost. Response cost or cost contingency consists of removing a desired item or reinforcer contingent on a specified undesired behavior. Thus, contingent on display of specific behaviors, tokens, free time, or privileges may be withdrawn (Table 11.10).

Time-Out. Time-out involves removing a person from a reinforcing situation contingent on display of specified maladaptive behavior. Time-out has been successfully used with students with ASD to reduce a variety of maladaptive behaviors. This strategy appears to be most effective when individuals understand that the procedure is used contingent on specific maladaptive behavior, and removal from reinforcement is for brief periods of time

TABLE 11.9
Example 9: Extinction Procedure

D. J. is a 8-year-old male with classic autism educated in a self-contained program for students with ASD. He exhibits a variety of socially inappropriate behaviors, including screaming, scratching, and spitting. D. J.'s spitting was of particular concern to the classroom teacher, and he had been sent home from school several times as a result. D. J. would spit and say "Go home and see mommy" and would, in fact, get to go home. As the behavior continued to escalate, it became obvious that D. J. was spitting in order to go home. An extinction program was implemented as a means of decreasing spitting. First, the target behavior was ignored. Moreover, the instructor encouraged D. J. to stay on task and ignored his request to "Go home and see mommy." The first day D. J. spat in excess of 250 times. The next day the spitting incidences were reduced by half. By the end of the week the incidence of spitting was zero. No further intervention was needed.

TABLE 11.10
Example 10: Response Cost

Consider the case presented in Table 11.8. After some time using the token economy system had passed, it was found that on occasion Eric engaged in off-task and self-stimulatory behavior. For example, he would sometimes begin to talk about unrelated subjects in a loud voice during individual work time. A response cost system was added to his token system to reduce the amount of talking out during this time. When he would begin to engage in the self-stimulatory behavior, he would be reminded verbally to return to work. This verbal reminder consisted of encouraging Eric to point to the icons on his desk, which prompted him to sit, work, and have a "quiet mouth." If Eric returned to work he was verbally praised. If he failed to return to work within 15 seconds, one token was removed. Once back on task, Eric had the opportunity to again earn tokens.

(e.g., 5 minutes of quiet time in a chair). Although time-out has been shown to be effective in modifying many behaviors in individuals with ASD, it is not universally effective. For example, time-out methods may be ineffective with self-stimulation, which often occurs independent of attention from others and which is often more reinforcing than are options available in an educational environment (Table 11.11).

Positive Practice/Overcorrection. Foxx and Azrin (1973) identified two major objectives of overcorrection (a) to overcorrect the environmental effects of an unacceptable behavior and (b) to require the person who engages in an unacceptable act to practice a correct form of an appropriate behavior (positive practice). Achieving the first objective, restitutional, requires "the disruptor to correct the consequences of his misbehavior by having him restore the situation to a state vastly improved from that which existed before the disruption" (Foxx & Axrin, p. 2). A child who turns over desks in his classroom, for example, might be made to reset the desks. Positive

TABLE 11.11
Example 11: Time-Out

Christy is an 11-year-old female with PDDNOS educated in a regular education sixth-grade classroom with special education support. Her favorite activities are related to music. A music class is part of her curriculum, and she looks forward to it. She is very dependent on routine and enjoys doing the same activities in music. Thus, she loudly and aggressively insists that the same activities occur in the same order during each music session. At times these behaviors escalate into aggression and tantrums. A time-out procedure was implemented to decrease the problem behaviors. When Christy began insisting on a particular activity, she was reminded to look at her music schedule. This consisted of icons in a photo album indicating the order of activities. If she continued to demonstrate the target behavior, she was removed from the music area and told that she could return when she was quiet and ready to participate. After being removed from the music group on two occasions, she was willing to participate in new activities presented in a different order.

TABLE 11.12
Example 12: Overcorrection

Damon is an 8-year-old male with classic autism educated in a self-contained classroom for students with developmental disabilities. He has limited verbalizations and can answer questions that are concrete in nature. For example, he can tell his teacher who is at school or what is for lunch, but is unable to tell why or how something occurs. He is toilet trained and can indicate the need to use the rest room. Damon sporadically engages in bizarre behaviors. Damon seems to enjoy instances when people observing the behavior react in a shocked or upset manner, and as a result, the behavior continues. On one occasion, Damon was observed urinating under his desk at school. When then teacher approached, Damon began to laugh hysterically. The teacher quietly put on rubber gloves and assisted Damon with putting on rubber gloves as well. Using hand-over-hand assistance, the teacher helped Damon to scrub the carpet for a period of 5 minutes where he had urinated earlier. She spoke to him while scrubbing, reminding him that he must urinate in the toilet. When the scrubbing was completed the teacher accompanied Damon into the bathroom where he demonstrated appropriate use of the facilities.

practice overcorrection, used to achieve the second objective, requires the student who turns over desks in the classroom to practice picking up items in the room. Restitutional overcorrection is applicable only when a behavior disrupts the environment. Overcorrection is designed not only to reduce unacceptable behavior but also to teach an individual an acceptable alternative. Although overcorrection is not always a suitable intervention, it appears to be a method that both assists in eliminating unacceptable behavior and teaches an appropriate alternative response (Table 11.12).

Differential Reinforcement of Other Behaviors (DRO). Differential reinforcement of other behaviors (DRO) involves reinforcing behaviors that are incompatible with, or are appropriate alternatives, to an undesired behavior

TABLE 11.13
Example 13: Differential Reinforcement of Other Behaviors (DRO)

Annie is a 10-year-old girl with classic autism, severe cognitive delays, and pica. The pica is severe enough to require constant adult supervision when she is in her self-contained classroom for children with autism. Annie is functionally nonverbal, but has learned to verbalize a few meaningful phrases including "Wanna eat." She repeats this throughout the day as she frantically seeks out objects to ingest, such as paper clips, staples, scraps of paper, or any small object. A functional analysis was used to identify Annie's preferred items. Based on this analysis, replacement items representing the preferred items were placed in a "pica box." For example, cotton candy was chosen because the cottony substance was similar to paper products she enjoyed consuming. Beef jerky was placed in the box to represent bark. When Annie exhibited the pica behavior, she was directed to her pica box and encouraged to choose an item to eat or chew. The box was always in view and over time Annie learned to independently obtain it. More importantly, her pica behavior significantly decreased.

(Skiba, Pettigrew, & Alden, 1971). Accordingly, maladaptive behaviors are weakened by having individuals attend to and reinforce appropriate alternative behaviors. Differential reinforcement takes several forms, including reinforcing an individual for engaging less frequently in an undesired behavior, reinforcing a person for engaging in behavior that is incompatible with an undesired response, and reinforcing a person for engaging in behavior that is more acceptable than the undesired one (Table 11.13).

Cognitive Behavioral Interventions

Cognitive–behavioral methodology developed in part as a result of a dissatisfaction with behavioral methodology and the development of social learning theory and the field of cognitive psychology (Maag, 1999). It has been widely noted that behavioral methodology has weaknesses in generalization and maintenance of treatment gains due to the fact that behavioral control is external in nature. This led to the view that Skinner's behavioral learning theory did not account for all human behavior and thus the development of alternative theories and approaches to behavioral management based on cognitive-behavioral theory in the 1960s and 1970s (Bandura, 1977; Lazarus, 1966; Mahoney, 1974; Meichenbaum, 1977; Neisser, 1967).

Most cognitive behavioral modification approaches are based on three assumptions: (a) cognitive activity affects behavior, (b) cognitive activity may be monitored and altered, and (c) desired behavior change may be affected through cognitive change (Dobson & Block, 1988; Maag, 1999). The use of cognitive behavioral interventions with students with ASD assumes that these individuals have both the capacity and the preference for monitoring and managing their own behavior (Heflin & Simpson, 1998). There has been an ever-growing body of research focusing on various interventions based

on this methodology throughout the last decade with promising results. There is no question that future research is needed to further validate the effectiveness of using cognitive behavioral strategies with children with ASD. Indeed, the exact role that these interventions play in enhancing children's social skills, in relation to other variables, is unclear. Nonetheless, based on preliminary findings, it appears that these techniques may have utility in individual and group settings for students with ASD who function at a variety of levels. Some of the cognitive behavior interventions that we view as having good promise for use with individuals with ASD include (a) self-management, (b) social stories, (c) cartooning, and (d) cognitive scripts.

Self-Management

Self-management programs are designed to teach individuals to manage their own behavior rather than to rely on external controls. Those who successfully learn to self-manage carry with them the cues and reinforcement needed to engage in appropriate behaviors. Self-management provides a sense of ownership and responsibility for behavioral choices and increases the likelihood that the appropriate behavior will last over time and generalize to settings besides the one in which the behavior was originally taught (Maag, 1999). According to Nelson, Smith, Young, and Dodd (1991), there are four types of self-management: (a) self-instruction (i.e., self-produced verbalizations), (b) self-monitoring and self-recording, (c) self-assessment or self-evaluation, and (d) self-reinforcement (student determines own type and amount of reinforcement). There is some empirical evidence that self-management interventions are effective with individuals with ASD (Koegel & Koegel, 1990; Koegel, Koegel, Quinn, Swaggart, & Myles, 1994; Stahmer & Schreibman, 1992; Shearer, Kohler, Buchan, & McCullough, 1996; Strain, Kohler, Storey, & Danko, 1994) (Table 11.14).

Social Stories

A social story describes social situations relevant to specific social cues and appropriate social responses. These individualized stories are often in the form of two to five sentences. Sentences include descriptions of a setting, individuals, and actions; directive statements describing recommended behavioral responses; and perspective sentences describing the feelings and reactions of persons involved in the situation (Gray & Gerard, 1993). Several studies have been published utilizing this intervention as an antecedent behavior management strategy, all of which reported that social stories were effective in improving targeted behavior (Hagiwara & Myles, 1999; Kuttler, Myles, & Carlson, 1998; Lorimer, Simpson, Myles & Ganz, 2002; Norris & Dattilo, 1999; Rogers & Myles, 2001; Swaggart et al., 1995) (Table 11.15)

TABLE 11.14
Example 15: Self-Management

Rachel is a 13-year-old female diagnosed with Asperger syndrome and attention deficit disorder educated in a general education middle school with the support of a inclusion specialist. She has a study hall once a day with the specialist. She has average intelligence, but has a difficult time getting good grades which is largely attributed to her difficulty with staying on-task. The inclusion specialist trained Rachel to self-manage using the following system.

Pretraining Preparation	Staying on task was targeted as the behavior Rachel would learn to self-manage and is broken down into three steps: (a) look at the task, (b) think about the task, (c) complete the task. Searching the internet was identified as the motivator that would be used, and an unobtrusive self-monitoring chart and visual reminder of the steps to staying on task that she could carry in a three-ring notebook was created.
Discrimination Training	Rachel and the inclusion specialist talked about why staying on-task was important and practiced examples and nonexamples of on-task behavior. Rachel was given a small portable tape recorder, earphones, and a tape with intermittent beeps (average 1 minute) and trained to mark her self-monitoring sheet every time the tape beeped and she was on task.
Self-Management Implementation	During study hall, Rachel self-monitored her on-task behavior along with the inclusion specialist. Her accuracy was checked 10 minutes before the end of each study hall session. If she was at least 90% accurate she received 10 minutes of Internet time.
Training Self-Management Independence	Tapes with fewer beeps were used each week until an average of 5-minute intervals were reached.
Treatment Withdrawal	Rachel stopped using the beep tapes and was given a small portable timer that she could set at 5-minute intervals.
Generalization	Rachel used the small portable timer during her English class in addition to study hall. Study hall also served as a natural time to determine if the system was working and provided review sessions as needed. Additional classes were added as time went on.

Cartooning

Cartooning is a type of visual support that helps to explain social events. Cartoons enhance social understanding by using visual symbols to turn abstract and elusive events into something tangible and static (Hagiwara & Myles, 1999). There have been several programs created using cartooning strategies, including comic strip conversations (Gray, 1994), mind-reading (Howlin, Baron-Cohen, & Hadwin, 1999), and pragmaticism (Arwood & Brown, 1999). There is some empirical evidence that supports the use of visual supports to teach skills to individuals with ASD (Dettmer, Simpson,

TABLE 11.15
Example 16: Social Stories

Kurt is an 8-year-old male diagnosed with autism educated in a self-contained classroom for students with emotional and behavioral disorders. He is nonverbal and often makes loud noises and jumps when anxious. This typically occurs when unpredictable things happen or when there is a change in his normal daily routine. The following social story was written for Kurt 1 week prior to a class field trip. He read it several times a day until the day of the field trip.

My Field Trip to Gifford Farm

On Friday after lunch, my class will go on field trip to Gifford Farm. Most students enjoy field trips and can learn many new things on them. First, we will get on the bus and drive to Gifford Farm. I can choose to sit by Mrs. Smith or Miss Johnson. When we get to Gifford Farm, we will all walk into a big room and sit on the floor on carpet squares. I will try to sit on my square with my legs crossed. Some people will bring out several different animals and tell us about them. I can choose to pet the animals or just look at them. Loud noises sometimes scare animals. I will try to be quiet. After we see the animals, we will get back on the bus and drive back to school. When we get back to school I can choose to read a book or do a puzzle.

TABLE 11.16
Example 17: Cartooning

Leonard is a 14-year-old middle school student diagnosed with high-functioning autism. Although generally successful in an inclusionary program, Leonard has difficulty accurately interpreting interactions that occur at lunch time and during passing periods. In particular, he has difficulty interpreting the kidding and humorous comments that occur. As a means of assisting Leonard with this problem the school counselor illustrates the interactions between him and his classmates using a cartoon format. Included in this process is an interpretation of what classmates were saying with their comments and responses Leonard might want to make as responses.

Myles, & Ganz, 2000; MacDuff, Krantz, & McClannahan, 1993) with two focusing specifically on cartooning (Parsons & Mitchell, 1999; Rogers & Myles, 2001) (Table 11.16).

Cognitive Scripts

Cognitive scripts are familiar, repeated events taught through direct instruction or learned incidentially in which some goal is achieved. Individuals with ASD have been successfully taught scripts to navigate their environment (Charlop & Milstein, 1989; Krantz & McClannahan, 1993, 1998; Loveland & Tunali, 1991; Sasso, Melloy, & Kavale, 1990). In addition, neurotypical peers have been taught to use cognitive scripts to solicit and/maintain social interactions with individuals with ASD with positive outcomes (Carr & Darcy, 1990; Goldstein & Cisar, 1992; Gonzalez-Lopez & Kamps, 1997; Kamps et al., 1992; Odom, Chandler, Ostrosky, McConnell, & Reacey, 1992; Pierce & Schreibman, 1995, 1997) (Table 11.17).

TABLE 11.17
Example 18: Cognitive Scripts

Leroy is a 7-year-old student who has a diagnosis of autism. Although he is able to use relatively age-normal language, Leroy generally prefers to talk about garage door openers and related matters (e.g., electric motors that open garage doors) with peers. This obsessive interest is of little interest to his peers; however, Leroy nevertheless focuses on this topic when with his classmates. In an effort to make this child more acceptable to his peers, his teacher prepared and practiced several comments that Leroy could make to his friends, including his preferred playground activities and TV shows he watches.

Novel Interventions

Many interventions for children and youths with ASD are well known for their nontraditional nature. Indeed, for more than any other group with disabilities, purported interventions for people with ASD have taken a number of forms, including facilitated communication, vitamin treatments, auditory integration training, and so forth. In this connection, the absence of efficacy documentation has been a significant problem for the field (Simpson & Myles, 1995). As a result, a number of efforts have been made to structure the advancement of unproven interventions for people with ASD (Simpson, 1995).

Arguments exist both for and against using unproven treatment methods with students with ASD. On the one hand, the use of any procedure that has the potential to assist a child with autism live a more independent and normal existence, regardless of whether researchers have validated its use, is easily defended. On the other hand, a number of organizations, families, and professionals are reluctant to commit significant resources to any intervention that has not been shown to be effective. Many families and professionals rightfully are requesting that individuals with whom they live and work be treated by means of the newest and most innovative methods available. Thus, these individuals are regularly demanding that any one of a number of undocumented methods be made a regular part of children's treatment and educational programs.

As noted earlier, a number of procedures that appear to have promise for individuals with ASD, but lack definitive support documentation, exist. In order to respond to the problems related to these purported treatments, it is imperative that the profession attempt to adopt guidelines and policies to evaluate the use of unproven intervention procedures. This appears to be especially important with regard to undocumented interventions whose claims for improvement far exceed any other available methods; where claims are made in the absence of sound research literature; and in situations where interventions are independent of rational, logical, theoretical positions. At the same time, however, such policies and guidelines must not

be so stringent as to interfere with the development of innovative and creative programs for people with autism. Accordingly, they should be designed to assist parents and professionals in making informed decisions regarding the use of innovative methods without obstructing the development of novel treatment strategies.

GENERALIZATION, MAINTENANCE, AND FOLLOW-UP STRATEGIES

Generalization, maintenance, and follow-up activities address the significant issue of transferring skills and responses from one setting to another. Individuals with ASD are well known for their deficits in this area, making generalization and transfer a particularly critical element in design and implementation for this population. For example, a student who has learned to manage his or her self-stimulatory behavior in his or her classroom with his or her teacher cannot be assumed to demonstrate the same control at home with his or her parents. Thus, generalization of this skill across settings and with various individuals needs to be taught. Indeed, it is highly likely that skill transfer will be limited without direct instruction.

SUMMARY

Children and youths with ASD display a variety of unique behaviors, including social interaction excesses and deficits, self-stimulatory behaviors, and marked preoccupation with restricted and stereotyped responses. As a result, management of children and youths with ASD is considered to be so significant that most treatment and educational considerations are either related to or secondary to establishing effective management and social interaction patterns: In this context, this chapter has presented several important considerations related to managing children and youths with ASD. Appropriate use of these elements, including structuring procedures, individualized management program development and implementation, and circumspect consideration of novel treatment options, is considered essential to the lives of people with ASD and their families.

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Chapter 12

Medical Treatment in Autism

Luke Y. Tsai
University of Michigan Medical Center

INTRODUCTION

Both behavioral and biological studies have generated sufficient evidence suggesting neurobiologic etiologies of autistic disorder. At present, however, no specific biological markers have been identified as the cause(s) of autistic disorder. Hence, etiologically based treatment or intervention has not been developed to "cure" individuals with autistic disorder. However, comprehensive intervention approaches including parental counseling, behavior modification, special education in a highly structured environment, social skills training, sensory integration training, music therapy, vocational training, and medical treatment have demonstrated significant treatment effects in many individuals with autistic disorder. The nonmedical treatments of autistic disorder have been described in other chapters of this book. The present chapter is written for parents and other caregivers of persons with autistic disorder with the intent of helping them gain more knowledge of when and how medical treatment (particularly medications) can be used as an important part of the comprehensive treatment of autistic disorder. For the purpose of presentation, the term *autism* will be used as a synonym of autistic disorder as defined by the *DSM-IV* diagnostic system (American Psychiatric Association [APA], 1994) throughout the remaining sections of this chapter.

GOALS AND APPROACHES OF MEDICAL TREATMENT

Prevention

The primary goal of medical treatment of persons with autism is to ensure their physical and psychological health. To accomplish this goal, preventive medical care is crucial. A good preventive health care system includes the following: (a) scheduling regular physical checkups by a medical physician with experience in taking care of individuals with autistic to monitor the individual's somatic growth, vision, hearing, blood pressure, and to administer scheduled immunizations; (b) arranging regular visits to the dentist to maintain dental hygiene and to prevent any dental disease; and (c) providing education on appropriate diet and nutritional needs to the persons with autism and their caregivers.

Early Detection and Treatment

The secondary goal of medical treatment of persons with autistic is to be able to do early detection and treatment of the unappealing and irritating behaviors, disturbed sleep and eating problems that develop in these individuals. These problematic behaviors or symptoms may be clinical manifestations of coexisting neuropsychiatric disorders or uncomfortable medical and dental conditions, or side effects induced by the psychotherapeutic medications taken by the individuals with autism. Early diagnosis and effective treatment of these disorders or conditions will significantly improve the quality of these individuals' lives.

Multidisciplinary Treatment Approach

When medical treatment is considered, it should be a multidisciplinary treatment approach that will integrate perspectives and recommendations of medical physicians (developmental neurologist, or developmental and behavioral pediatrician, or psychiatrist), parents, psychologists, special education teachers, speech and language pathologists, occupational therapists, physical therapists, and other caregivers. A major part of medical treatment is the use of medication (i.e., psychopharmacotherapy using psychotherapeutic medications). The prescription and management of medication should be done by a physician specializing in developmental, behavioral, and psychiatric disorders. The physician should work closely with the individual with autism, his or her family members, and with other professionals involved in the care of the individual. This is the only way to ensure that

the most effective use of medication is achieved with minimum risk of side effects or complications.

Complete Functional Behavioral Analysis

A complete functional behavioral analysis must be carried out by a qualified and experienced behavioral therapist before the initiation of a psychotherapeutic medication because some of the conditions or symptoms may be learned or maladaptive behaviors that usually do not respond to psychotherapeutic medications. Such an approach will enable a more realistic expectation to the extent that the chosen medication may be effective (Tsai, 2001).

CAN MEDICATION CHANGE BEHAVIOR AND EMOTION?

In the past, it was widely believed that individuals were in complete control of their feelings and behaviors. Much has changed and continues to change in our understanding of the causes of troubling behaviors or emotions in humans. Neurobiological and neuropsychological studies in the last 3 decades have demonstrated that the causes of behaviors and feelings are extremely complex. Nonetheless, it is quite clear now that the body and the mind are not two separate systems; rather, there are complex interrelationships between the two. Many "problem behaviors" and "disturbed emotions" may be caused, at least partially, by neurobiological dysfunction. For example, there is evidence supporting the notion that abnormal behavior or disturbed emotions involve abnormal neural communication in the form of an abnormal metabolism or the abnormal function of neurotransmitters. (*Neurotransmitters* are chemical substances responsible for the transmission of signals between synapses.) Researchers are identifying which neurotransmitters travel through specialized neural networks in the brain.

Neuroscientists have identified several types of neurotransmitters including catecholamine transmitters (epinephrine, norepinephrine, and dopamine), serotonin, acetylcholine, γ-aminobutyric acid (GABA), and certain other amino acids and neuropeptides. Epinephrine and norepinephrine appear to be involved in emotional states such as arousal, rage, fear, anxiety, pleasure, stress response, motivation, and exhilaration. In addition, they also impact cardiovascular and respiratory function, eating and drinking, neuroendocrine regulation, activity level, selective attention, movement, memory, cognition, and learning. Dopamine is crucial to every voluntary movement, and also is involved in cognition, eating and drinking,

neuroendocrine regulation, sexual behavior, and selective attention. Serotonin seems to play a crucial role in sleep and wakefulness, in certain types of sexual activity, and perhaps in modulating and balancing a wide range of synaptic activities such as body temperature, pain, sensory perception, immune response, motor function, neuroendocrine regulation, appetite, learning, and memory.

Every single behavior or emotion may involve several neurotransmitters. Nonetheless, at present, it is acceptable to emphasize a one-to-one relationship in terms of further understanding the neurobiological etiology of various neuropsychiatric disorders as well as develop effective psychopharmacotherapy based on such a relationship. To that extent, neuroscientists have found that altered central dopaminergic function in the midbrain is considered the principal neurotransmitter system implicated in the pathogenesis of Tourette disorder (TD). Psychotherapeutic medications such as haloperidol (Haldol) and pimozide (Orap) are dopaminergic blockers, which may restore the balance of dopamine in the particular neural circuit and decrease the tic symptoms.

In individuals with too much norepinephrine, everything gets pumped up, and every stimulation demands a response. β-Blockers such as propranolol (Inderal) block receptors for norepinephrine. With less adrenaline igniting their brain circuits, these individuals can calm their anxiety. On the other hand, a shortage of norepinephrine seems to rob people of the ability to pay attention to what is important. The well-known stimulant, methylphenidate (Ritalin), can increase the availability of norepinephrine in children with attention deficit hyperactivity disorder (ADHD) and restores their ability to pay attention to what is important, and only to what is important.

Shortage of serotonin in the frontal lobes and in the brain's limbic system (where emotions come from) seems to relate to impulsivity. Individuals with inadequate serotonin are unable to connect disagreeable consequences with what provoked them. A serotonergic defect involving the basal ganglia may cause obsessive–compulsive symptoms in some people. The well-known psychotherapeutic medication, fluoxetine (Prozac), is a serotonin reuptake inhibitor (SRI) that can increase the availability of serotonin in the particular neural network relating to obsessive compulsive disorder (OCD) to improve the symptoms.

PSYCHOPHARMACOTHERPY IN AUTISM

Currently there are strong data showing that certain psychotherapeutic medications are quite effective as a first-line treatment for certain neuropsychiatric disorders (e.g., ADHD, OCD, tic disorders, affective disorder, anxiety

disorder, seizure disorders, and sleep disorders) that may develop during the course of autism in some individuals. On the other hand, the psychopharmacological field has also compiled sufficient knowledge of side effects that may be produced by ingesting the psychotherapeutic medications. The study of these neuropsychiatric disorders in the last 20 years certainly has helped the field of autism. Many of the "behavioral problems" or "disturbed emotions" may be clinical manifestations of coexisting neuropsychiatric disorders that will be described later or side effects induced by the psychotherapeutic medications taken by individuals with autism (more information on drug-induced side effects will be described later). Early detection and effective treatment of these coexisting neuropsychiatric disorders or medication-induced side effects are critical because the improvement of the psychiatric or behavioral symptoms will enhance the positive response to other forms of intervention in these individuals and allow learning to take place. Thus, a rational use of psychotherapeutic medications will enhance the individual's ability to participate in educational, social, vocational, and family systems.

Like most medications, psychotherapeutic medications can correct or compensate for some malfunctions in the human body or systems. They do not cure autism, but they do lessen the burden of ailments to persons with autism.

BASELINE MEDICAL ASSESSMENT

Effective medication treatment begins with a thorough medical assessment. The pretreatment assessment is essential for detecting many medical conditions such as seizure disorder, meningitis, lead poisoning, brain tumors, endocrinological disorders, and chromosomal abnormalities that can cause or exacerbate behavioral, emotional, communicative, or cognitive problems in persons with autism. The pretreatment assessment is also essential for establishing the baseline physical, psychological, behavioral, and cognitive status prior to medication treatment.

The following sections describe the methods of gathering information for medical assessment and diagnosis in individuals with autism.

Interviewing and Observing Behaviors

Formal and informal interviews and observation of behaviors comprise one method for gathering in-depth information about the child, parents, caregivers, and interaction among them. Child-rearing methods, discipline, and parental or caregiver's attitudes and perceptions of their child's behavior, can be explored. The commonly used interview formats include the

following: unstructured interview, structured interview, semistructured interview, symptom checklists, and computer-based interview.

Interviewing the Parents, Caregivers, and Child

Such an interview will allow the child to hear the caregivers' concerns of his or her challenging behaviors. If the child's cognitive and communication skills are adequate, such an interview would also give the child an opportunity to give his or her reasons for having the "challenging behaviors." However, due to being young or having limited cognitive and communicative skills, the child may not understand the reason for the assessment and may be unable to adequately express himself or herself. Nonetheless, he or she should be respected as a participant of the assessment process and be given an opportunity to listen to the concerns. Such an interview also provides the opportunity to observe the interaction between the caregivers and the child. Most observations of such interactions include both structured and unstructured time. With younger children, for example, parents may be provided a variety of toys and asked to "play with your child as you would at home." After a few minutes they can be instructed to "have the child put away all the toys." Older individuals and their parents or caregivers can be asked to play a board game, draw a picture together, or talk about a family vacation plan.

Observing the individual's behaviors in such a setting would provide information on his or her developmental level in terms of cognition, social skills, and problem-solving skills. With permission from the caregivers and the child, this interaction session should be videotaped and used for later diagnostic feedback. It can also be used as the pretreatment baseline that will be compared with the posttreatment changes.

Interviewing the Parents and Caregivers

Obtaining pertinent information from the caregivers without the presence of the child is of vital importance. It provides a vehicle to go over more sensitive information with the caregivers, as well as to understand the caregivers' perception of the problems and their influence on both the child and his or her environment (i.e., home and family life, classroom and learning, or job place and work performance). The parent or caregiver interview also provides an opportunity to follow up on information gathered from the previously completed checklists and questionnaires. The physician will review the child's developmental history (past and present cognitive, physical, adaptive, and social functioning), past medical and psychiatric history (previous diagnosis, treatments), and family medical and psychiatric history.

Interviewing the Child

The individual diagnostic interview is often the most difficult obstacle for the physician who is not used to the evaluation of individuals with autism. This difficulty is frequently due to anxiety over preconceived differences in this population and the assumption that the individual cannot provide useful or valid information about his or her challenging behaviors or symptoms. In fact, there are some individuals with autism who are verbally capable of relating as long as the language is kept simple. Of vital importance is the establishment of rapport with these individuals. Hence, knowledge of the cognitive–developmental characteristics of individuals at different ages and appropriate interview skills are essential to conducting a successful interview with a verbal individual with autism. The interview with a verbal individual provides valuable information on the individual's perception of himself (interests, fears, strengths, weaknesses, self-confidence), the environment (family, peers, school, job place, and co-workers), and the presenting problems, as well as on how the child attempts to cope with and solve personal and interpersonal problems. The language used during the interview should be at or just above the child's cognitive and language level. Age-appropriate, unstructured materials (crayons, pencils, papers, books, Legos, Play-Doh, doll house, etc.) should be provided for the young child to play with to make him or her comfortable while talking to the physician.

When interviewing older children, the physician should introduce topics of interest that are developmentally appropriate (e.g., TV shows or cartoon characters, sports, popular songs or movies, or computer games). When the individual becomes more comfortable with the interviewer, the physician will then slowly shift the focus of interview to the concerns of his or her parents or caregivers.

For individuals who are nonverbal, or who have difficulty with the verbal interview, nonverbal interactions should be used to assess capacity for social interaction. The individual's use of alternate communication systems, such as gesturing, sign language, or communication pictures or symbol boards, should be ascertained and assessed for his or her skill in using these systems. If feasible, these communication means should be further used to gather subjective information from these individuals.

Observing the Child

Direct observation has been defined as the contemporaneous recording of spontaneously occurring, externally observable behavioral events. It is highly objective and provides an accurate portrayal of clinical relevance. Observation of a child's selection of play materials and how the child plays with them can be a valuable source of information about his or her intellectual and language development, special interests, leisure time skills,

social relationships and interaction skills, feelings, thoughts, worries, and anxieties. Such a method is particularly important and useful in gathering information from nonverbal, lower functioning, or very disturbed and uncooperative individuals.

Cognitive development, fine motor development, language development and skills, organizational skills, creativity, symbolic and pretend play skills, attention span, distractibility, impulsiveness, compliance, persistence, use of help, frustration level, emotional expression, perceptions of family interaction, and problem-solving skills can be assessed through observing the child playing with toys such as Legos, dollhouse, and simple rule-governed games. The previously cited information is useful for assessment of developmental disorders, ADHD, oppositional defiant disorder (ODD), and conduct disorder (CD).

Direct observation can also record behaviors such as crying or whimpering, inactivity, withdrawal, agitation, stuttering, tremors, and nervousness. These behaviors may relate to depressive or anxiety disorders. From observational data, areas in which more formalized testing are needed can be identified.

Home and School Observation

Some individuals may not exhibit the challenging behaviors or symptoms at the physician's office, or the information contained in the videotape provided by the parents or caregivers may not helpful diagnostically. If resources are available (i.e., the physician has a well-trained staff who specialize in behavior observation and assessment), an observation of the child's behavior at home, in school, or on the job should be carried out.

Physical and Neurological Assessment

Because different behavior problems, symptoms, or side effects of medications may mimic other medical or psychiatric disorders, the physical and neurological assessments may reveal medical problems or disorders previously missed; new, unrelated medical problems or disorders; incorrect earlier diagnoses; or adverse effects associated with various treatments. It is very important to make an accurate differential diagnosis that will directly impact on the nature and course of medication to be prescribed. The other major reason for a careful and complete physical and neurological assessment is to establish the baseline physical and neurological status prior to medication therapy for monitoring and prevention of the development of side effects.

Simple measures such as recording of both standing and supine blood pressure, pulse, height, and weight (e.g., weight loss caused by stimulant and

weight gain caused by neuroleptics) should also be included. A complete documentation of present illness, past medical history including immunizations and hospitalizations, medical review of systems, history of allergies, other prescribed or illicit drug or alcohol use, and a family neuropsychiatric history should be done. It should be emphasized here that the aforementioned assessment procedures should be continuous throughout the course of the treatment to ensure the efficacy of psychopharmacotherapy.

Problems Encountered During Physical and Neurological Assessment

Performing a complete physical and neurological assessment in some individuals with autism can be a real challenge, and the physician needs special training and experience in working with these individuals. This is particularly true in individuals with low cognitive and communicative functions. It may be impossible to explain the examination procedure to them to get their cooperation during the assessment. Some individuals may resist any physical contact and may even react violently to the usual examination procedure. The assistance of parents or caregivers who are familiar with the individual's behavior patterns and means of communication can be most helpful. In some really difficult cases, the physician may have to compromise with the situation and focus on just obtaining the essential information, or may have to rely on recent documentation of another physician's physical examination obtained when the individual was cooperative.

Laboratory Tests

Role of Laboratory Tests

Although the laboratory tests can never replace clinical acumen in any medical specialty, they can play a significant role in explaining and quantifying biological factors associated with various medical and psychiatric disorders. The role of the laboratory tests in the evaluation of behavioral problems has become increasingly prominent as a supplement to the crucial clinical history and physical examination. In some individuals, supplementary laboratory and diagnostic tests may be needed when specific clues from the history, physical examination, or initial laboratory screens or tests suggest a medical or psychiatric condition that might have caused or exacerbated the behaviors or symptoms of concern. Judicious use of laboratory parameters may thus be valuable to the physician in answering specific questions of evaluation.

Avoid Unnecessary Laboratory Tests

Not all the laboratory measures and tests promoted by nonmedical professionals or the media need to be done as routine screens or tests. Particularly, many tests recommended by advocacy groups or media tend to be new tests that may not be supported by scientific evidence demonstrating that they meet minimum criteria of effectiveness. Inaccurate, false-positive results can cause profound anxiety and require additional testing that can be increasingly invasive and costly. They can also deplete society's limited medical resources. Physicians can and should refuse to order tests that would violate their medical and ethical judgment.

On the other hand, some physicians who do not have much knowledge, training, and experience in working with individuals with autism may order unnecessary medical tests. The parents or nonmedical caregivers should inquire the reason(s) for the tests and how the results aid in the assessment or intervention of the child. Physicians have a responsibility to inform the caregivers of the limitations and risks of the tests they would like to pursue. If the caregivers are not satisfied with the explanation(s) given by the assessing physician and if there is no life-threatening urgency, they should seek a second opinion before agreeing to take the tests.

It is the physical condition of the child and the physician's medical knowledge and experience that determine which laboratory tests should be done to aid the assessment. Wasteful laboratory tests that have limited clinical utility should be avoided.

It can be said that very few diagnoses of mental or psychiatric disorders can be confirmed by current laboratory tests. Hence, laboratory studies should be ordered only for (a) specific diagnostic considerations (e.g., thyroid studies to evaluate depression) and (b) baseline assessment where the proposed medication(s) could alter organ systems (e.g., assessments of thyroid function before lithium is instituted).

The following section focuses only on the utility of the more commonly considered laboratory measures in evaluating behavioral problems. The main function of these laboratory tests described in the following is to support or confirm the clinical diagnoses of certain medical or neurological disorders that also have behavioral symptoms as part of the clinical manifestations. The other function of these tests is to confirm that the behaviors of concern are side effects of psychotherapeutic medication(s) taken by the individual with autism.

Electrocardiogram. Assessment of the heart's electrical conduction or cardiac monitoring via the electrocardiogram (ECG) is an integral part of the assessment of anxiety disorder and drug-induced side effects such as

those that occur as a result of treatment with tricyclic antidepressants in children and adolescents.

Electroencephalography. A complete electroencephalography (EEG) and neurological consultation should be obtained when there is a deteriorating course, a clear history of seizure, or when the medical history and neurological examination indicating space-occupying or infectious brain symptoms and signs (e.g., staring or spacing spells, fainting spells, dizziness, headaches, numbness, tingling, tremors, weakness, clumsiness, speech problems, pain, and motor or vocal tics). Thus far, however, no specific EEG patterns have been identified that can accurately aid in the diagnosis of a particular psychiatric condition.

Catecholamine and Enzyme Assays. Catecholamines are assayed in a 24-hour urine collection in individuals with anxiety. Accompanying abnormal levels of autonomic function should be screened for pheochromocytoma (a type of kidney tumor). In individuals taking antipsychotic medications who are being evaluated for the development of neuroleptic malignant syndrome (NMS; characterized by fever, muscle rigidity, stupor, and autonomic dysfunction), blood levels of creatine phosphokinase and white cell counts should be performed.

Brain Imaging. At present, the routine use of imaging studies is not indicated in individuals with behavioral disorders. However, computerized tomography (CT) or magnetic resonance imaging (MRI) is considered clinically useful for ruling out brain tumors and for mapping signs of increased intracranial pressure, changing or degenerative neurological signs, craniofacial malformations, suspected syndromes, or inherited syndromes that include CNS structures. Positron emission tomography (PET) is helpful in the presurgical evaluation of individuals with intractable epilepsy.

Lumbar Punctures. Clinical pictures of altered mental status consistent with cerebral spinal fluid (CSF) infection warrant examination of CSF with lumbar puncture.

Electromyogram and Nerve Conduction Studies. Electromyogram (EMG) and nerve conduction studies may help individuals in whom myopathies or peripheral neuropathies are suspected but clinically were misinterpreted as psychiatric symptoms (e.g., conversion hysteria).

Polysomnography. Polysomnography (PSG) refers to sleep recordings that monitor various physiological parameters (usually nighttime). It is

useful in the investigation and diagnosis of sleep disorders, especially sleep apnea and narcolepsy.

Metabolic Screening. Many metabolic disorders may cause behavioral or emotional changes. For example, Wilson's disease, a recessively inherited disorder of copper metabolism, in adolescents may cause incongruous behaviors, personality change, cognitive impairment, anxiety, and depression. Its identification (low serum ceruloplasmin level, low total serum copper level, and raised urinary copper excretion) is critical because it is a treatable metabolic disorder.

Thyroid Function Tests. If thyroid disease is suspected to be contributing to a disorder that has symptoms including anxiety, depression, mental retardation, dementia, restlessness, mental status change, and psychosis, screening tests of thyroxine and triiodothyronine resin uptake should be conducted. Thyroid-stimulating hormone levels should be determined if results are abnormal or barely normal. A thyrotropin-releasing hormone stimulation test may be considered if initial studies are ambiguous.

Liver and Kidney Function Tests. When particular medications are being questioned as affecting the individual's liver or kidney functions that in turn might cause the behaviors of concern, the liver or kidney functions should be evaluated. An example is lithium treatment which can affect kidney function.

Serum Measures. It should be mandated that children on newer drugs such as Clozaril (an antipsychotic medication) be given regular, complete blood counts. Tests for serum amylase and electrolyte values may be useful in the assessment and follow-up of bulimic patients.

Chromosomal Analysis. It has been suggested that a deficit in cognitive development is influenced by abnormal numbers of X chromosomes. There have also been associations between increased numbers of Y chromosomes and increased risks of behavioral problems, most notably impulsiveness and immaturity. Genetic measures may be helpful. Testing for a fragile X chromosome may be helpful in individuals with mental retardation and abnormal physical characteristics.

Illicit Drug Screening. For individuals with new-onset behavioral changes or psychotic symptoms, testing for drug abuse may be helpful.

Toxicology Screening. Lead ingestion, though rare, can be measured as a potential cause of behavioral difficulty.

Speech and Language and Cognitive Function Assessments

Psychotherapeutic medications and anticonvulsants may alter speech and language development or performance (e.g., neuroleptics, stimulants, and tricyclic antidepressants can alter speech production, rate, volume, and coherence) in persons with autism. Psychotherapeutic medications may also affect these individuals' cognitive function or performance (e.g., fenfluramine may have a retarding effect on discrimination learning). It is important to have a documentation of baseline speech and language and cognitive functions. These assessments should be carried out by a qualified and experienced speech pathologist and a psychologist, respectively.

CLINICAL DIAGNOSIS

Given these multiple sources of information, diagnostic evaluation requires more than a simple compilation of data. It involves a process of analysis and synthesis that brings together the results of all the data analyses by each of the interdisciplinary team members so that an accurate picture of the individual's condition is formed. Much of the information related to the behavior of concern (e.g., developmental status, social context, parental and caregiver's health and perception of the individual and behavior of concern, antecedents and setting events, and consequence of the behavior) has been assessed prior to the referral for a medical assessment and diagnosis. If the conclusion from a previous functional behavioral assessment is considered as accurate and acceptable, the interdisciplinary team should focus on information gathered during the medical assessment process. However, the team should take into consideration that how the individual performs in a variety of settings or contexts may be quite different from performance observed by professionals during structured testing sessions. The assessment information must be interpreted in terms of the individual's total functioning, including both abilities or strengths and disabilities or weaknesses. This process leads to a judgment about the significance of the challenging behaviors and results in the classification of a specific disorder.

Initial Diagnostic Impression

Having obtained the necessary information from subjective and objective sources, the next step is the development of a preliminary diagnostic impression based on the *ICD-10* or *DSM-IV*. It serves the purpose of labeling and referring to either the individuals' complaints or to the parents' or caregivers' concerns. It also provides a way of conceptualizing complaints within

the framework of our current knowledge, so that appropriate treatment can be instituted. Although we have not yet attained the ideal of specific drugs for specific diagnostic categories, we do know which classes of existing drugs are likely to be effective in certain diagnostic groups, and which of the existing drugs are contraindicated for certain medical and psychiatric disorders.

Development of an Intervention Plan

The interdisciplinary team of specialists then jointly prescribes a comprehensive intervention plan that may include psychotherapy, behavior therapy, speech therapy, occupational therapy, activities therapy, and pharmacotherapy for the individual and his or her parents or caregivers. Often there is also the need to consider and treat more than one challenging problem or symptom. The intervention plan should prioritize the identified challenging behaviors or symptoms and decide which behavior or symptom should be dealt with first.

GENERAL APPROACHES TO PSYCHOPHARMACOTHERAPY

Psychopharmacotherapy begins with establishing the relationship between behavioral abnormalities (i.e., symptoms) and underlying biochemical abnormalities (e.g., depletion of certain neurotransmitters). The goal of psychopharmacotherapy is to correct both with an effective chemical agent (i.e., medication). However, based on the contemporary definition and classification systems, autism is viewed as a heterogeneous syndrome. Hence, it is heterogeneous both behaviorally and biochemically. Until the cause—effect relationship in autism becomes clear, the aim of psychopharmacotherapy of autism will be for a rational intervention. For example, it is believed that OCD is related to serotonin functions. Hence, clomipramine (a serotonin uptake inhibitor) is used in autism individuals with severe repetitive behaviors or stereotypies, significant clinical features of OCD. To achieve the goal of effective rational medication treatment in autism, it is also essential to learn about the basic principles of psychopharmacotherapy; the workups for use of various medications; basic categories of medications; the indications and contraindications of each medication; the measuring of medication effects; and recognition, management, and prevention of medication induced side effects.

Basic Principles of Psychopharmacotherapy

1. Psychopharmacotherapy should begin with a functional behavioral analysis and be followed by a thorough medical diagnostic assessment.

2. A careful history, thorough physical and neurological examination, and some laboratory data should be obtained for evaluation and be used as the baseline preceding the medication treatment.

3. Medication treatment should never be used as the first and sole intervention. Medication therapy should be just a part of a comprehensive intervention that includes psychosocial interventions (including family counseling and individual and group therapies), cognitive therapy, behavior therapy, special education intervention, occupational therapy, speech and communication therapy, sensory integration treatment, and music therapy.

4. Medication treatment should be reserved for individuals with severe behavior problems or emotional disturbances who fail to respond or only partially respond to other nonmedical interventions.

5. When there are multiple behaviors or emotional concerns, the treatment priority should be determined by the treatment team. If at all possible, treatment should begin with one medication for the most urgent problem.

6. Appropriate selection of psychotherapeutic medication is based on multiple factors including medical factor, patient and family factor, physician factor, social factor, and economic factor.

7. Some people may respond better to one medication than to another. Some may need larger dosages than others. Children differ significantly from adults in their pharmacokinetic capacities.

8. Whenever possible, the physician should prescribe medication that will be taken in a single daily dosage.

9. Whenever possible, the pharmacist should be asked to dispense tastier medications to enhance the compliance of taking medications. Whenever the medications are taken orally, they should be taken with water or another liquid.

10. The individual being treated should be involved in the treatment process as much as possible, despite his or her age and level of functioning. Every effort should be made to help the individual to understand the reason and purpose for taking the medication(s) and the possible development of side effects from the medication(s). Sensitive counseling can help overcome any fears of taking medication that the child may have. This approach will prevent the development of negative attitude or misperception toward the use of the medication in these individuals. When this is done, the individual with autism becomes a useful and helpful ally in the intervention.

11. The parents and other caregivers should always be included in the entire process from initial evaluation through monitoring medication effects, and final termination of medication treatment.

12. Valid and clinically meaningful measures should be implemented regularly to assess therapeutic effects and side effects of psychotherapeutic medications.

13. How frequently the individual being treated should be seen by the physician and how long he or she should be on the psychotherapeutic medications depend on the phase and the nature of the individual's disorder or problems of concern as well as on the action of the medication.

14. Termination of medication treatment may be initiated by the patient, his or her parents or legal guardians, the prescribing physician, or by mutual agreement. At this juncture, the potential for recurrence should be clearly discussed in the context of the risk–benefit ratio.

PHARMACOTHERAPY AS A SCIENCE

Concepts of pharmacotherapy have been greatly advanced by clinical investigators who make careful and controlled observations on the outcome of therapeutic interventions. Over the past 3 decades, the principles of human experimentation have been defined, and the techniques for evaluation of pharmacotherapy have progressed to the point that therapies now are dominated by objective and scientific evaluations.

However, pharmacotherapy as a science does not apply simply to the assessment and testing of new, investigational medications in animals and human beings. It applies with equal importance to the treatment of each person as a unique individual. Physicians of every discipline have long recognized and acknowledged that individuals show wide variability in response to the same medication. Progress has been made in identifying the sources of variability. The following sections discuss the strategies that have been developed to deal with variability in clinical settings.

Individualized Pharmacotherapy

Like any other medication, psychotherapeutic medications do not produce the same effect in everyone. Some people may respond better to one medication more than to another. Some may need larger dosages than do others. Age, sex, body size, body chemistry, habits, and diet are some of the factors that can influence a medication's effect. Furthermore, the safety or efficacy of a medication in an individual is never assured. Because individuals differ in their responses to medications, each therapeutic encounter must be considered an experiment with a hypothesis that can be tested. The scientific basis of the hypothesis derives from the database generated from controlled clinical trials during drug development and the experience obtained

postmarketing. For example, a physician now would assume his or her patient's problems with OCD are due to impairment of serotonin regulation. To test the hypothesis of the cause of the patient's problem, the physician would use a medication (e.g., Prozac) that usually increases the amount of serotonin going through the neuron synapses. If the patient's symptoms improve significantly with the administration of Prozac, the physician's hypothesis would be supported by the treatment result.

When pharmacotherapy is being considered as a necessary intervention to modify the child's behaviors or symptoms, his or her physician faces two important decisions: (a) the initial choice of a specific medication and (b) the initial dosage. Optimal treatment results will be achieved only when the physician knows the child's diagnosis, severity and stage of the problem or disorder, presence of concurrent disorders or medication treatment, as well as the sources of variation in response to medications and predefined goals of acceptable efficacy and toxicity. Of utmost importance is that prior to the therapy, well-defined endpoints of treatment and the means to assess the achievement of the goals must be established. If objectively assessable expectations of individualized medication therapy are not set before therapy is initiated, therapy is likely to be ineffective and continued longer than necessary.

Choosing an Effective Medication

Clinical Considerations

In most clinical settings, the decision about the choice of medication is influenced substantially by the confidence the physician has in the accuracy of the diagnosis, estimates of the extent and severity of the disease, and previous experience with certain disorders and medications used to treat those disorders. Based on the best available information, the physician must decide on an initial medication from a group of reasonable alternatives. Many factors, including a cost–benefit analysis of diagnostic tests of the efficacy (e.g, test for blood level) and monitoring of side effects (e.g., EKG monitoring for cardiac side effects), availability and specificity of alternative therapies (e.g., melatonin for certain types of sleep problems), and the likelihood of a reduction in future utilization of expensive health care (e.g., use of lithium to prevent relapse of mania and readmission to an inpatient unit), influence the assessment of selecting the medication.

Pharmacokinetic Considerations

Variation in pharmacokinetic properties of a medication among individuals must be taken into account in choosing a medication regimen. For

some medications, this variability may account for one half or more of the total variation in eventual medication response. The relative importance of the many factors that contribute to these differences depends in part on the medication itself and on its usual route of elimination. Medications that are extensively metabolized with high metabolic clearance and large first-pass elimination have marked differences in bioavailability, due to physiological and pathological variations in organ function (e.g., kidney or liver diseases). In such cases, measurements of concentrations of medications in blood can be helpful in the individualization of medication therapy.

Individualizing Dosage

To design a rational dosage regimen, the clinician must have some knowledge about rates of absorption and distribution, steady-state concentration, and half-life of the medication being considered. Moreover, the physician must judge what variations in these parameters might be expected in a particular individual and make appropriate adjustments.

Determination of Dosage Regimen

The initial dosage regimen is determined by estimating the pharmacokinetic properties of the medication in the particular individual. The estimate must be based on an appreciation of the variables that are most likely to affect the disposition of the particular medication. Subsequent adjustments may be aided in some instances by measuring medication concentrations but must ultimately be based on whether the medication positively changes the individual's behaviors or symptoms without inducing any adverse effects or having just acceptable levels of side effects. The efficacy of a medication treatment can also be defined as the benefit it produces plus the dangers of not treating the disorder minus the sum of the adverse effects of the therapy. Another common expression of the usefulness of a treatment is its ratio of risks to benefits.

Dosing Interval

In general, marked fluctuations in drug concentrations between doses are not beneficial. If absorption and distribution were instantaneous, fluctuation of drug concentrations between doses would be governed entirely by the drug's elimination half-life. If the dosing interval were chosen to be equal to the half-life, then the total fluctuation would be twofold; this is usually a tolerable variation. For example, the half-life of Ritalin is about 2 to 4 hours, and it is a common practice to take Ritalin every 4 hours. If a medication is relatively nontoxic, such that concentrations many times those

necessary for therapy can be tolerated easily, the maximal dose strategy can be used, and the dosing interval can be much longer than the elimination half-life. For example, when 10 mg of Adderall is effective about 4 hours, giving 15 to 20 mg may increase the effective interval to about 6 hours. However, for some medications with a narrow therapeutic range, it is important to estimate the maximal and minimal concentrations that will occur for a particular dosing interval to avoid toxicity.

Titration

To determine the optimal dosage for an individual, many researchers and clinicians prefer to titrate dosage; that is, the medication is administered by beginning treatment with relatively low doses (most likely therapeutically ineffective). Then either the dose is increased by increments every few days to a point at which they reach therapeutic effectiveness or higher doses become contraindicated by side effects. If therapeutic effects are not obtained at the highest recommended dose or if severe side effects emerge and interfere with the desired changes, the usual next step is to use another medication from the same general class of medication.

Loading Dose

The "loading dose" is one or a series of doses that may be given at the onset of therapy with the aim of achieving the target concentration rapidly. A loading dose may be desirable if the time required to attain steady state by the administration of a medication at a constant rate is long relative to the temporal demands of the condition being treated. For example, in acute mania, 10 mg or more of Hadol may be given every 1 to 2 hours to stabilize the individual. Afterward, 2 to 5 mg of Haldol can be given every 4 to 6 hours.

However, the use of a loading dose also has significant disadvantages. First, the particularly sensitive individual may be exposed abruptly to a toxic concentration of a medication. Moreover, if the drug involved has a long half-life, it will take a long time for the concentration to fall if the level achieved is excessive. Loading doses tend to be large, and they are often rapidly given by intravenous or intra-arterial injection and. This can be particularly dangerous if toxic effects occur as a result of actions of the medication at sites that are in rapid equilibrium with plasma.

Dosage Adjustment

When long-term therapy is needed, there may be questions such as how often to change dosage and by how much. There is a simple rule of thumb: Change dosage by no more than 50% and no sooner than every 3 to 4 half-lives each time. For example, if an individual has been on 4 mg of

Risperdal (half-life of 24 hours) daily for a few months, the next dosage increase should not be more than 6 mg daily. The individual should be on that dosage for at least 96 hours before further adjustment of dosage can be made. On the other hand, some medications have very little dose-related toxicity, and maximum efficacy is usually desired. For these medications, doses well in excess of the average required will ensure both efficacy and prolonged medication action.

Monitoring Dosage Regimen

Monitoring the medication response of the individual using predefined goals for acceptable efficacy and toxicity requires close attention. Some adverse events are avoidable if therapy is individualized. However, other serious adverse reactions are related to an interaction of the medication with variables unique to the individual. When a medication is first marketed, it has been tested in only a limited number of well-characterized patients. Hence, the information on drug interactions is usually not available for newly marketed drugs.

Monitoring Therapeutic Concentration of Medication

A fundamental hypothesis of clinical pharmacokinetics is that a relationship exists between the pharmacological response to a medication and the accessible concentration of the medication in body fluids such as plasma, urine, saliva, and CSF. Although in some medications there are no clear or simple relationships between pharmacotherapy effect and concentration in body fluids (particularly plasma), there are a limited number of medications clearly showing such relationships. Determinations of concentrations of medication in blood, serum, or plasma are particularly useful when there is a demonstrated relationship between the concentration of the medication and the eventual therapeutic effect that is desired or the toxic effect that must be avoided. There is, however, substantial individual variability in disposition of the medication that makes the prediction of drug concentration from dose alone almost impossible. Furthermore, there is some disagreement in the research literature as to whether there is a clear relationship between medication concentration in the blood and clinical response to that medication. Another concern in the use of blood level is the lack of agreement on the clinically useful range of blood concentration indicative of therapeutic change. Nonetheless, measurement of blood levels may provide a drug index that can be related to changes in specific behaviors, to prevent serious side effects, and to identify drug treatment nonresponders.

Therapeutic Range

In some medications the desirable ranges of steady-state concentrations have been determined (i.e., therapeutic range). In general, the lower limit of the therapeutic range appears to be approximately equal to the drug concentration that produces about half of the greatest possible therapeutic effect. The upper limit of the therapeutic range is determined by toxicity, not by efficacy. Generally, the upper limit of the therapeutic range is such that no more than 5% to 10% of individuals on the particular medication will experience a toxic effect. For some medications, this may mean that the upper limit of the range is no more than twice the lower limit. Of course, these figures can be highly variable, and some individuals may benefit greatly from drug concentrations that exceed the therapeutic range, whereas others may suffer significant toxicity at much lower values. The center of the therapeutic range is usually chosen as the target.

For some medications with a narrow therapeutic range, doses must be titrated carefully, a target level of steady-state concentration of the medication should be chosen, and a dosage is computed that is expected to achieve this value. Drug concentrations are subsequently measured, and dosage is adjusted if necessary to approximate the target more closely.

Factors That Affect Outcome of Pharmacotherapy

Many factors can influence the individual's response to a medication, including the age of the individual; disease of the organs of drug elimination (e.g., kidney and liver); the concurrent use of other medications, foods, and chemicals (i.e., drug interactions); previous therapy with the same or similar medication (i.e., medication tolerance); and a variety of genetic factors that can influence the kinetics and toxicities of medications (i.e., pharmacogenetics).

Measure of Medication Effects

Dosage regulation of any medication depends on reliable measurement of changes or improvements of targeted behaviors. However, in most cases of autism, patients are unable to report their symptoms or their response to treatment accurately. Furthermore, a positive treatment effect may be a decrease in the frequency or severity of long-standing maladaptive behavior, and this change may not be readily apparent in the clinician's office. Therefore, the measuring of treatment response must rely on objective techniques that are reliable (i.e., repeatable over time or across observers) and valid (i.e., reflect what is actually being measured) for data collection from caregivers.

There are various measurement techniques that can be employed. These techniques include direct behavioral observations, behavioral rating scales, self-reports, standardized tests, learning and performance measures, mechanical movement monitors, and global impression. On the other hand, it is also crucial that the assessment strategies are sensitive to changes produced by the medication and are practical, economic, safe, and ethical.

Direct Behavioral Observations

Behavior is recorded as it happens with frequent reliability checks, and assessment results are often graphed to aid interpretation. This type of assessment can be carried out either in an artificial situation (e.g., a child taking an intelligence test) or in a natural situation (e.g., a child's home or classroom). The major limitation with this procedure is that it is expensive in terms of staff time.

Behavioral Rating Scales

The most commonly employed method in modern psychopharmacology is the use of behaviors or symptoms rating scales. However, very few rating scales have been developed specifically for the assessment of medication effects in individuals with autism. At present, in their daily practice of treating individuals with autism, physicians tend to use rating scales that have been developed for non-ASD populations. These scales are generally problem-oriented checklists that are completed by parents or caretakers familiar with the individual with autism. This is a quick, efficient, inexpensive, and practical procedure that is used frequently in almost all clinical settings. There are many rating scales with established reliability, validity, and sensitivity to medication changes including the Aberrant Behavior Checklist (Aman & Singh, 1986), the Children's Psychiatric Rating Scale (National Institute of Mental Health, 1985), the Child Behavior Checklist (CBCL; Achenbach, 1991), Clinical Global Impressions (CGI; *Psychopharmacology Bulletin*, 1985), Conners Checklist (Conners, 1976), the Emotional Disorders Rating Scale for Developmental Disabilities (Feistein, Kaminer, Barret, & Tylenda, 1988), the Ritvo–Freeman Real Life Rating Scale for autism (Freeman, Ritvo, Yokota, & Ritvo, 1986), and other symptom- or disorder-specific rating scales (Tsai, 2001).

Self-Reports

This procedure has a limited application in the autistic population due to general difficulties in cognitive and communicative functionings of autistic people. In addition, the self-report tends to have low agreement with others' evaluation of the behavior. Nonetheless, some higher functioning

older individuals with autistm can report their own symptoms/behaviors or respond reliably to a self-report questionnaire such as the Children's Depression Inventory (Kovacs, 1991) and the Childhood Anxiety Frequency Checklist (Reiss, Peterson, Gursky, & McNally, 1986). The self-reports should be incorporated into the assessment of medication efficacy.

Standardized Tests

All the standardized clinical tests such as intelligence tests, school-attainment tests, language and speech tests, and specific psychological tests (e.g., visual–motor integration test) have been used to assess medication efficacy, particularly in long-term studies. These tests, however, are generally insensitive to short-term changes produced by medications, except for the Porteus Maze Test (Aman, 1978). School achievement tests can be used in young and higher functioning children with autism when psychotherapeutic medication is given over a period of months or years.

Learning and Performance Measures

Psychotherapeutic medications may have an impact on learning, either by removing behavioral and emotional impediments (resulting in improvements) or by producing sedation, confusion, or other uncomfortable side effects (resulting in worsening of clinical conditions). For this reason, performance tests may be considered useful in monitoring an individual's progress while on longer term medication treatment. These include assessments of sustained attention, selective attention, short-term memory, task completion, and rate of performance before and after administration of certain medication. The material to be learned or processed is often novel (e.g., paired associate learning) and used for that test only; the subject is required to perform at that point in time. Frequently, performance tests are controlled by electronic equipment, such as personal computers. These measurements are appropriate for short-term medication trials. These measures include Continuous Performance Task (CPT; Aman, 1978), Cancellation Tasks (Aman & Turbott, 1986), Matching Familiar Figures Task (MFF; Kagan, 1965), and Serial Recall: Assessment (Watkin, Craig, & Gallagher, 1990).

Mechanic Monitors

These are devices (e.g., computerized activity monitor and videotapes) used primarily to measure the changes of functions and activities of autonomic nervous system caused by certain medication. For example, pressure sensors mounted under carpeting and connected with a computer to measure hyperactivity and general motor activity in children; an actometer

attached to the wrist or waistline of hyperactive children to measure the hyperactivity and its changes when they were awake and asleep; videotapes of patient's examination, interview, or free-play rated by independent raters. Of all the options, the wrist actometer is of greatest interest to practitioners, but its validity has been questioned, especially when activity is sampled over brief intervals. It also has other problems including resetting by the individual, the need for frequent recalibration, and breakdowns during vigorous activity. Most mechanical devices are presently too cumbersome and expensive for routine clinical use.

Global Impression

An individual's overall behavior is judged by global impression. This is the most frequently used and least reliable method for evaluating the medication efficacy. It fails to capture day-to-day variability, and it cannot be replicated across time or clinicians. Clinical Global Impressions (Campbell & Palij, 1985a) and Nurse's Global Impression (Campbell et al., 1978) are examples of the scales that have been used in previous studies.

Monitoring of Other Medication Effects

Periodic laboratory screening should be done on a regular basis during the entire duration of medication therapy. It is judicious practice to repeat complete blood cell count (CBC) and differential, urinalysis, and basic blood chemistry screening at 3 months and at every 6 months for each of the medications. Blood pressure and pulse rate should be checked weekly. Serial EKG should take place whenever a medication with significant cardiovascular effects is prescribed. Weight and height should be recorded on a monthly or quarterly basis.

In summary, it is important in monitoring the medication effects that a decision be made based on data and information obtained from as many sources as possible. Such an approach can help to avoid problems caused by a biased informant as well as by placebo effect.

Recognition of Side Effects Caused by Psychopharmacotherapy

In the pharmacological treatment of autism, we tend to focus more effort and attention on establishing the efficacy of psychotherapeutive medications. However, all the psychotherapeutic medications have the potential to produce adverse reactions. Although the mandate of the Food and Drug Administration (FDA) is to ensure that medications are safe and effective, both of these terms are relative. The anticipated benefit from any

therapeutic decision must be balanced by the potential risks. Because only a few thousand patients are exposed to experimental drugs in more or less controlled and well-defined circumstances during new medication development, medication-induced adverse events that occur as frequently as 1 in 1,000 patients may not be detected prior to marketing. Hence, recognizing and managing side effects of the psychotherapeutive medications are also crucial in the optimal use of the psychotherapeutic medications. Side effects may range from a minor nuisance to a potentially fatal reaction. If unrecognized, the medication-induced side effects can affect patient outcome adversely, in terms of both medical and psychiatric well-being. This is particularly true in individuals with autism. Because of their cognitive and communication disabilities, they may not be able to comprehend or to recognize the medication-induced side effects, and hence are incapable of alerting or informing their caregivers about the development of the side effects. They may become frightened or suspicious if a sudden change or dysfunction occurs following the administration of medication(s). Such feelings may trigger tantrums or interfere with compliance. It has been reported that psychotherapeutic medication-induced side effects are the reason for discontinuation in 25% to 33% of those who stop treatment. Therefore, the importance of actually monitoring drug response cannot be overemphasized.

Prevention of Development of Side Effects

It is essential that the clinician be knowledgeable about the full range of side effects of the medication(s) being prescribed and knows how to manage side effects should they arise. In general, "mechanism-based" adverse drug reactions or side effects (e.g., a decrease in blood pressure when using clonidine [Catapres] to treat ADHD due to Catapres' antihypertension pharmacological property) are relatively easier to predict based on preclinical and clinical pharmacology studies. However, the relatively rare and severe "idiosyncratic" adverse reactions (e.g., severe dermatologic, hematologic, or hepatologic toxicities), which result from an interaction of the medication with unique host factors that are unrelated to the principal action of the medication, are more difficult to predict. In addition, it is clear that a population risk of the rare "idiosyncratic" adverse reactions is not distributed evenly across the population. Some individuals, because of unique genetic or environmental factors, are at an extremely high risk, whereas the remainder of the population may be at low or no risk. Understanding the genetic and environmental bases of idiosyncratic adverse events will certainly improve the overall safety of pharmacotherapy. The following are general guidelines to avoid the development of side effects:

1. Obtain a complete family history including medication treatments and responses and a complete medical history (including responses to previous medication treatment) of the patient.
2. Treatment should begin with one medication.
3. Avoid giving the same medication that had demonstrated previous side-effects in the individual.
4. Avoid giving *preventive* anti-side-effect medication, such as antiparkinsonian agent.
5. If the patient does not respond to the medication of first choice, it is discontinued gradually while a second medication is instituted and its dosage is increased.
6. Use the lowest possible maintenance doses in the therapeutic range once it has been established.
7. If indicated, regularly monitor the blood level of the medication, blood counts, blood pressure, pulse rate, EKG, liver function, height, and weight.
8. Regularly perform a complete physical and neurological examination and monitor side-effects using published side-effects rating scales.
9. After the optimal effect of a medication has been established, give periodic drug holidays, at least once every 4 to 6 months.
10. When a decision of discontinuation of a medication has been made, in most cases, the medication should be tapered and withdrawn gradually.

It is also critical to alert and educate parents and caretakers regarding the potential side effects of the chosen medication as well as the therapeutic benefits. When a psychotherapeutic medication or anticonvulsant is prescribed, the person with autism, his or her family members, and other caretakers should ask the following questions recommended by the U.S. Food and Drug Administration and professional organizations:

- What is the name of the medication, and what is it supposed to do?
- How and when should one take it, and when should one stop taking it?
- What foods, drinks, other medications, or activities should one avoid while taking the prescribed medication?
- What are the side effects, and what should one do if they occur?
- Is there any written information available about the medication?

Side Effects of Psychotherapeutic Medications

The following section describes medication-induced side effects and management options. Because multiple side effect can be caused by one

medication and that same type of side effect can be produced by many different psychotherapeutic medications, there is not enough space here to describe which side effect tends to be induced by what medications. The following section only describes commonly seen psychotherapeutic medication-induced side effects and some suggestions on the management of the side effects. One general strategy for dealing with psychotherapeutic medication-induced side effects is to change the medication if possible.

Behavioral Effects

Psychotherapeutic medication-induced behavioral side effects may develop insidiously over a long period of time (e.g., dependence) or may behave in an idiosyncratic and unpredictable fashion (e.g., a switch to mania). The behavioral side effects include:

1. *Jitteriness syndrome* (inner restlessness or a "wired" feeling, irritability, increased energy, and insomnia). Most patients develop tolerance to this jitteriness side effect once the initial dose is lowered or discontinued. Low doses of benzodiazepines may be helpful in alleviating the initial jitteriness.
2. *Sedative effect* (ability to cause tiredness and to initiate sleep). The offending medication should be taken in divided doses during the day or switched to a less sedating medication.
3. *Impaired memory.*
4. *Disinhibition, hostility, and aggression.*
5. *Switch mania* (depressed patients become manic). When depressed bipolar patients are being treated with a tricyclic antidepressant (TCA) or a monoamine oxidase inhibitor (MAOI), another antidepressant should be given simultaneously to reduce the risk of switching to mania.
6. *Paranoid psychosis.* Initially, the psychosis manifests by paranoid ideas, auditory hallucinations, hyperactivity, and irritability with a clear sensorium. Prolonged use may cause a withdrawn, disorganized, dysphoric state. The psychotic state usually clears within 1 week of discontinuation of the offending medication.
7. *Work and school phobia.*
8. *Sleep disturbances* such as nightmares or disturbing dreams accompanied by temporary confusion and disorganization, somnambulism (appearing confused and walking about in a quick, detached, and clumsy manner), and quasi-hallucinatory hypnagogic episodes. The sleep disturbances may disappear spontaneously. If the disturbances persist, doses should be switched to daytime.
9. *Initial and middle insomnia*, and *afternoon tiredness* and *sleepiness* (*somnolence*). Insomnia may respond to a short-acting hypnotic antihistamine,

or a sedating antidepressant such as trazodone. Daytime somnolence may require discontinuation of the medication.

10. *Withdrawal reactions* (nausea, vomiting, diarrhea, abdominal cramps, malaise, cold sweats, chills, dizziness, headache, insomnia, anxiety, panic attacks, sleepiness, fatigue, hunger, depression, and autonomic hyperactivity of tachycardia, hypertension, sweating, and restlessness). If the withdrawal symptoms are mild, they usually subside within a few days. In more severe cases, a small dose of the discontinued TCA or MAOI may be given and repeated after 1 hour if only partial improvement is obtained after the first dose.

11. *Dependence.*

Neuromuscular Effects

These include:

1. *Muscle tension, tremor, twitching, cramps,* or *muscle pains* can develop. These symptoms are usually mild. In severe cases with muscle cramps or pains, cyproheptadine may be helpful.

2. *Myoclonus* (brief jerks of the lower extremities, usually in the evening during relaxation; repetitive jaw jerking, causing stuttering; sudden arm jerking, resulting in dropped objects). In most cases myoclonus is mild. In severe cases, clonazepam, valproic acid, or carbamazepine may be helpful.

3. *Nocturnal myoclonus* (repetitive violent jerky contraction of the legs). Nocturnal myoclonus sometimes responds to dose reduction, or to medications for myoclonus such as carbamazepine, clonazepam, and valproate. A switch to another medication is advised in cases that fail to respond to the previously cited measures.

4. *Tremor of upper extremities* and occasionally of the *tongue.* If a dose reduction does not help, propranolol may be tried.

5. *Impaired motor function* such as decline in speed, accuracy, attention, and coordination (ataxia); falls and impaired automobile driving.

6. *Extrapyramidal symptoms* (*EPS*; so-called because they result from disturbances in the brain structures affecting bodily movement, excluding motor neurons, the motor cortex, and the pyramidal tract). The symptoms consist primarily of (a) *acute dystonia* (intermittent or sustained muscular contraction or spasm that may produce an abnormal posture or involuntary movements). The muscles of the head, neck, or trunk are rigid or cramping. Bizarre postures or gait may be the results of the involvement of extremities. Sustained contraction of the masticatory muscles can produce facial grimacing, opening of jaw, and protrusion of the tongue. In oculogyric crisis, the patients may have a fixed, blank stare, which is followed by an upward and lateral rotation of eyes. Blepharospasm with sustained eye closure may

occur. During these events, the head may be tilted backward (retrocollis) or sideways (torticollis) with the mouth opened. These reactions may last from a few seconds to several hours. The treatment of the reactions with an anticholinergic agent or an antihistamine (given either intravenously or intramuscularly) usually provides relief in minutes. Benzodiazepine may also be helpful. If the antipsychotic medication cannot be discontinued and the patient is not already on standing doses of an antiparkinson agent, this should be started. A 7-day course of antiparkinson agents at the start of neuroleptic therapy has been recommend to prevent acute dystonic reaction (Winslow, Stiller, Coons, & Robinson, 1986). (b) *Neuroleptic-induced parkinsonism* is characterized by bradykinesia or akinesia, tremor, and rigidity. The tremor is a coarse "pill-rolling" or "to-and-fro" rhythmical movement which is greater at rest. Rigidity is most apparent in the limbs, where a cogwheeling resistance is noted during passive movement. The previously cited symptoms and signs may present in varying degrees and combinations. Onset of this syndrome may occur after the first week of treatment, but usually within the first month (Kane, 1989). The anticholinergic-type antiparkinson drugs (benztropine, biperidinetrihexyphenidyl, procyclidine) are the most extensively used medications. Antihistamines (e.g., diphenhydramine) and dopamine-releasing agents (e.g, amantadine) can be considered when the anticholinergic–antiparkinson drugs are not effective. (c) *Acute akathisia* (an inability to sit still or an intense subjective sense of restlessness). If the dose of the neuroleptic cannot be reduced or the neuroleptic cannot be discontinued, propranolol or other lipophilic beta-adrenergic blocking agents may be helpful (Fleischhacker, Roth, & Kane, 1990). If other forms of EPS are present, anticholinergic antiparkinson drugs should be used first.

7. *Akinesia* (diminished arm swing and narrow gait, slow and monotonous speech, diminished gestures, more passive behavior and fewer emotional displays, social ineptitude, impaired cognitive function, decreased creativity, and lack of interest in work). Once the diagnosis is established, if possible, the dose of the neuroleptic drug should be lowered. The other option is to initiate or increase the dose of an antiparkinson agent. A third treatment option is to stop the neuroleptic drug and to change to a lower potency neuroleptic agent.

8. *Tardive dyskinesia* (frequent, repetitive, involuntary movements of the lips, tongue, jaw, face, and sometimes trunk or limbs). The abnormal involuntary movements may increase with emotional arousal or during activities requiring repetition of motor activities or attention to fine motor tasks. Attempts to consciously control the symptoms may increase the movements. The movements may decrease with relaxation. The movements are entirely absent during sleep. The abnormal movements should be present for at least 4 weeks. Several medications (clozapine, clonidin, propranalol, bezodiazepines, sodium valproate, vitamin E) have shown some treatment

effect, but further studies are needed to establish their efficacy in the treatment of tardive dyskinesia. At the present time, no proven safe and effective treatments are available for tardive dyskinesia; therefore, until a satisfactory treatment is found, the prevention and early diagnosis of the potentially socially disruptive symptoms associated with this disease must be emphasized. Physicians should examine patients regularly (every 3–6 months) for early signs of tardive dyskinesia. Effective prevention also lies in cautious use of neuroleptic drugs given at the lowest effective dose.

9. *Neuroleptic malignant syndrome* (NMS; severe muscle rigidity or catatonia; instability of the autonomic nervous system including hypertension or labile blood pressure, tachycardia or bradycardia, cardiac arrhythmias, dilated pupils, prominent diaphoresis, incontinence of feces or urine; hyperthermia in the range of 101–104°F, and altered mental status ranging from agitation and alert mutism to stupor or even coma). There may be associated choreiform movements, dyskinetic movements, a festinating gait, and flexor extensor posturing. Use of lower average doses of a neuroleptic may prevent the development of NMS. Early diagnosis, rapid drug discontinuation, institution of intensive supportive care, or use of dopamine-augmenting drugs (e.g., amantadine, L-dopa, and bromocriptine) have reduced the fatality rate significantly (Caroff & Mann, 1988).

Convulsive Effects

Seizures are rare, but serious side effects of a number of psychotherapeutic medications have been reported. Seizure side effects are more likely to be reported with newly marketed medications than with an older agent with which the risk of seizure is accepted (Dessain et al., 1986). Generally, the lower potency neuroleptics may be prone to induce epileptic seizure activity (Baldessarini, 1985). There are certain features in individuals that may lead one to suspect the possibility of a medication-induced seizure:

1. Patients with a present or past history of seizures
2. Those with a family history of epilepsy
3. Patients on multiple psychotherapeutic medications
4. Postnatal brain damage
5. The use of certain agents that are considerably more likely to cause seizures

If a patient on a psychotherapeutic medication develops a seizure, one must screen for medical or neurological illness before making the assumption that the seizure is due to a psychotherapeutic medication. One must approach an event that appears to be a seizure in a patient on a

psychotherapeutic medication in a methodical and rational manner, and not abruptly change therapy unless it is felt to be ineffective.

To prevent a medication-induced seizure, the physician should (a) avoid high doses or rapid upward titration, (b) avoid psychotropic polypharmacy, and (c) not abruptly discontinue the patient's benzodiazepine. Patients with poorly controlled epilepsy may be more at risk for aggravation of seizure secondary to psychotherapeutic medications. More conservative psychotherapeutic medication dosing should be given in this group. Prior to instituting a psychotherapeutic medication, one should measure anticonvulsant serum level and use low-risk medications (e.g., thioridazine or mesoridazine).

Cardiovascular Effects

These include:

1. *Hypertensive reaction* (mild form manifested by mild headache or palpitation; severe form, by a sharp rise in blood pressure often with systolic levels over 200 mm Hg and diastolic pressure levels over 120 mm Hg, accompanied by a severe throbbing headache, flushing, sweating, palpitations, chest discomfort, a choking sensation, photophobia, nausea, and vomiting). If untreated and sustained, intracranial hemorrhage may occur, which can be fatal. In mild cases with hypertensive reaction, the treatment includes rest, reassurance, observation with blood pressure monitoring, and discontinuation of the medications. In severe cases (e.g., severe pounding headache, systolic pressure above 200 mm Hg and diastolic pressure above 115 mm Hg), medication treatment (e.g., phentolamine, diazoxide, nifedipine) should be considered (Clary & Schweizer, 1987: Cockhill & Remick, 1987).

2. *Orthostatic hypotension* (i.e., diastolic blood pressure drops more than 15 mm Hg from lying to sitting positions). The newer nontricyclic antidepressants such as bupropion fluoxetine and trazodone have a lower rate of orthostatic hypotension.

3. *Conduction delays* (increased PR, QRS, or QT interval in ECG). Generally, these delays are not clinically significant. However, it can be dangerous when they occur in patients with preexisting conduction disease, particularly bundle branch block. The newer antidepressants such as trazodone, bupropion, and fluoxetine can be the drugs of choice in treating these patients' depression.

Gastrointestinal Effects

These include:

1. *Xerostomia* (*dry mouth*). Most patients experienced some improvement of xerostomia over time. Prolonged period of xerostomia may result in

difficulties with chewing, swallowing, speaking, denture fit, increased risk of dental caries, candidiasis, or acute sialoadenitis. Treatment should begin with the elimination of medications known to induce xerostomia or the substitution of less anticholinergic drugs. Chewing sugarless gum or sucking on hard candies stimulates saliva production. Artificial saliva (e.g., Salivart, Moi-Stir) may be helpful in some patients.

2. *Dysphagia* (problem either with initiating swallowing or with transferring food from mouth to the upper esophagus resulting in nasal or oral regurgitation or coughing while eating). Dysphagia may result with significant weight loss, aspiration, and asphyxiation.

3. *Gastroesophageal reflux* (gastric contents reflux into the esophagus causing regurgitation, a sour or bitter taste in the mouth, heartburn, chest pain, aspiration with choking, wheezing, and coughing. Prolonged gastroesophageal reflux can cause esophageal ulcerations and can lead to bleeding or stricture formation.

4. *Nausea, vomiting, anorexia, abdominal pain, diarrhea, and increased salivation* caused by withdrawal of psychotherapeutic medications. The withdrawal reactions are generally mild, usually occur within the first week after discontinuation, and last for several days. Gradually tapering the dose may reduce the risk of such reactions.

5. *Constipation or abnormal distension* resulting in paralytic ileus, megacolon, pseudo-obstruction, or actual mechanical obstruction. If patients need to take the offending medications for prolonged periods of time, bulk laxatives, stool softeners, or osmotic agents should also be used.

6. *Diarrhea.*

Endocrine and Metabolic Effects

These include:

1. *Weight gain.* Most commonly, weight gain is a result of increased food intake, often accompanied by craving sweets and other carbohydrates (Stein, Stein, & Linn, 1985). Drug-induced weight gain can distress patients and leads to noncompliance with medication. There is no satisfactory treatment of medication-induced weight gain, aside from substituting a different medication or discontinuation of the medication. Occasionally, an anorectic agent (e.g., d-amphetamine or fenfluramine) may be helpful.

2. *Hyperprolactinemia.* Prolonged elevation of prolactin may cause galactorrhea or decline in the follicle-stimulating hormone (FSH) and leutenizing hormone (LH) released by the pituitary gland with subsequent diminution of ovarian function (or testicular function in man), leading to anovulatory cycles and infertility, menses with abnormal luteal phases, or amenorrha and hyperstrogenemia (Reichlin, 1992). Men with hyperprolactinemia

frequently develop impotence with loss of libido, even in the presence of normal testosterone levels (Ghadirian, Chouinard, & Annable, 1982).

3. *Hypothyroidism.* If a patient develops hypothyroidism while responding positively to a psychotherapeutic medication treatment, a reasonable approach is to add exogenous thyroid hormone (LT_4) in dosages that will maintain normal thyroid-stimulating hormone (TSH) levels.

4. *Nephrogenic diabetes insipidus* (NDI; polyuria and polydipsia). Most patients with lithium-induced NDI tolerate the polyuria and require no intervention from a physician. Drug should be discontinued in patients with severe NDI in which continued water intake cannot match with urine loses. If the medication cannot be discontinued, amiloride (a potassium-sparing diuretic; Kosten & Forrest, 1986) or indomethacine (Weinstock & Moses, 1990) can be used to treat the NDI.

5. *Hypercalcemia.* The increase of serum calcium level usually is mild. When the increase is more than 1.5 mg/dl or when the patient becomes symptomatic (e.g., polyuria, myopathy, anorexia), the medication should be discontinued.

Hematologic Reactions

These include:

1. *Aplastic anemia* (completely empty bone marrow resulting in anemia with weakness, shortness of breath, palpitation, angina, and loss of energy, leukopenia, and thrombocytopenia; leukopenia-related bacterial and fungal infection; and thrombocytopenia with bleeding into the skin in the form of ecchymoses or purpura, or from the mucous membranes and body apertures). Aplastic anemia is the most serious of the medication-induced disorders because of its high rate of mortality. If a patient is proved to have aplastic anemia, the suspected medication should be discontinued immediately and the patient should be promptly referred for a bone-marrow transplant procedure.

2. *Agranulocytosis* (decrease in white blood cells) may be asymptomatic at first but later develops symptoms such as sore throat, fever, chills, and drenching sweats. If the offending medication is continued, death from sepsis may occur.

3. *Eosinophilia* (increased percentage of eosinophils in a peripheral blood smear, which may exceed more than 6% of the total white blood count [WBC], or whenever total eosinophils exceed 3.0×10^9/L) is a major sign in a variety of medication-induced systemic disorders. It is recognized chiefly as a hematologic abnormality in skin rashes progressing to exfoliative dermatitis, but may occur in other hypersensitivity states, such as vasculitis, pulmonary infiltration, asthma, respiratory failure, pulmonary fibrosis, disseminated

intravascular coagulation, and purpura fulminans. Diagnosis is usually made when the clinical symptoms are promptly improved if the offending medication is discontinued but recur with rechallenge.

4. *Thrombocytopenia* (diminished number of platelets). When platelets are significantly fewer than 20×10^9/L), severe hemorrhage from the mucous membrane or into the central nervous system may occur. With milder thrombocytopenia, trauma may cause bleeding at the sites of injuries in the form of petechiae, purpura, or ecchymoses. If thrombocytopenia occurs, the offending medication should be discontinued.

Hepatic Effects

Psychotherapeutic medications can produce liver disease that is clinically, biochemically, and sometimes pathologically difficult to distinguish from acute viral hepatitis, chronic hepatitis, obstructive jaundice, cirrhosis, or primary biliary cirrhosis. Drug-induced hepatic injury may be classified as predominantly hepatocellular or predominantly cholestatic. The symptoms of hepatocellular hepatotoxicity are similar to acute viral hepatitis (i.e., nausea, fatigue, and anorexia; Zimmerman & Ishak, 1987). Hepatocellular degeneration, necrosis, or steatosis may result and may progress to death. Clinically and biochemically, medication-induced cholestasis may mimic obstructive jaundice.

Genitourinary System Effects

These include:

1. *Polyuria.* This is mainly caused by the use of lithium. Patient education is an important aspect of managing lithium-induced polyuria. The goal is to avoid fluid restriction. Thiazide diuretics may be used to reduce urine volume to a tolerable level. However, because thiazide may increase serum level, lithium dosage may need to be reduced. Should diuretics not work or not be tolerated, the use of indomethacin should be considered.

2. *Incontinence and enuresis.* If the offending agent can be discontinued, no other treatment is necessary. Even with medication continuation, some patients will spontaneously become continent. If problems persist, consultation with a urologist should be considered.

3. *Urinary retention with decreased frequency of urination, difficulty voiding, suprapubic discomfort, and reduced bladder sensation.* Dosage reduction or medication discontinuation usually should reverse the problem. Should difficulties arise in patients taking low-potency antipsychotics (e.g., chlorpromazine, thioridazine), either dosage reduction or changing to a less anticholinergic higher potency medication (e.g., haloperidol, thiothixene) may be all that is necessary. However, switching to a high-potency neuroleptic

drug may increase the risk of extrapyramidal side effects leading to the use of antiparkinson drugs (potent anticholinergics). The use of an alternate medication such as amantadine could be considered. Acute episodes of retention may require catheter decompression of the bladder. If continuation of the antidepressant is necessary, the use of a cholinergic agonist such as bethanechol will often relieve symptoms (Everett, 1975).

4. *Renal failure.* Acute renal failure has been reported following overdose with a variety of psychotherapeutic medications (e.g., amoxapine, loxapine, carbamazepine). Maintaining a high rate of urine flow with intravenous saline may reduce the risk of renal failure following overdose of these medications.

Reproductive and Adverse Sexual Effects

Psychotherapeutic medications may interfere with human sexual physiology and response by a variety of mechanisms including decreased or increased libido, decreased or increased erection and congestion–lubrication, decreased emission, and delayed or inhibited orgasm. They may cause impotence, menstrual irregularities, amenorrhea, gynecomastia in males, breast enlargement or galactorrhea, and testicular swelling.

In summary, there are wide ranges of reporting prevalence of psychotherapeutic medication-induced side effects. Therefore, for most psychotherapeutic medications, it is not currently possible to predict in advance which patients are at risk for developing clinically relevant complications by using psychotherapeutic medications. There is also a great variability among the side effects due to lack of universally acceptable definitions of the side effects. It remains a challenge to clinicians in differentiating where medical or psychiatric symptoms end and where the medication-induced side effects begin. Future studies must attempt to characterize more clearly these putative side effects and to validate their existence.

Monitoring Emergence of Side Effects

Rating Scales. Standardized and user-friendly rating scales for monitoring the various medication-induced side effects in autism have not been developed. Much of the current information on measuring and monitoring medication-induced side effects is derived from adult data, and many of the instruments were developed for nonautistic adults and are not necessarily appropriate for individuals with autism, particularly children. Thus, for young individuals, it is recommended to select specific target symptoms (e.g., repetitive behavior rather than compulsive disorder) at which medication treatment is targeted, and then to "customize" a checklist for that specific medication by listing expected side effects. Such rating scales are

essential for future prospective and systematic research in terms of collecting reliable and usable data.

Nonetheless, there are a number of general and specialized rating scales that can be applied or adapted to the autistic population. The following are some general-purpose rating scales: Adverse Drug Reaction Detection Scale (ADRDS; Corso, Pucino, DeLeo, Calis, & Gallelli, 1992), the Dosage Record and Treatment Emergent Symptom Scale (DOTE; Guy, 1976a), NIMH Systematic Assessment for Treatment Emergent Events (SAFTEE-GI; Campbell & Palij, 1985b), and Monitoring of Side Effects Scale (MOSES; Kalachnik, 1988). The following are some side effects of specific scales: Abnormal Involuntary Movement Scale (AIMS; Guy, 1976b), Barnes Akathisia Rating Scale (BARS; Barnes, 1989), and Dyskinesia Identification System Condensed User Scale (DISCUS; Sprague & Kalachink, 1991).

Use Videotaping to Monitor the Side Effects. In some instances videotaping an individual during his or her usual activities, or during a rating evaluation, can be quite helpful, especially if done before medication treatment and repeated at intervals.

Classes of Commonly Used Medications in Autism

It is important for persons with autism and their caretakers who use both medical and mental health services to become well informed about medications for neuropsychiatric disorders. The following section briefly describes classification, indication of use, and common side effects of some commonly used medications in autism. The recommended medication and dosage for each neuropsychiatric disorder or condition including seizure disorders are described in Table 12.1.

Antipsychotics

Antipsychotic medications are a large group of psychotherapeutic medications mainly known for their antipsychotic clinical properties, though they are also effective in a variety of nonpsychotic disorders. Another term often used for these medications is *neuroleptics.*

Antipsychotic medications interact selectively with the receptors of a variety of classes of neurotransmitters in the brains of humans. These include receptors of dopaminergic, serotonergic, α-adrenergic, histaminergic, and cholinergic systems, as well as of calcium channels. Within the dopaminergic system at least five types of receptors have been identified and different antipsychotics have differing affinities for these receptors as they do for other types of receptors. The most important variations in receptor action to consider are in the adrenergic and cholinergic systems because they influence

TABLE 12.1
Drugs Used in Autism and Associated Medical and Psychiatric Disorders

Complication or Disorder	*Generic Name (Brand Name)*	*Suggested Initial Daily Dose (mg)*	*Suggested Later Daily Dosage*		*How to Take*[a]
			Range (mg)	*(mg/kg)*	
Attention Deficit & Hyperactivity	Methylphenidate				
	(Ritalin)	0.3/kg	10–60	0.3–1.0	BID, TID[b]
	(Ritalin SR)	20	20–60		QAM
	(Ritalin LA)	20	20 –60		QAM
	(Concerta)	18	18–54		QAM
	Dextroamphetamine				
	(Dexedrine)	0.15–0.3/kg	5–40	0.15–0.5	BID, TID
	Amphetamines				
	(Adderall)	2.5–5	5–40		BID, TID
	(Adderall XR)	10	10–30		QAM
	Clonidine				
	(Catapres)	0.05	0.2–0.4		BID, TID, QID
	Guanfacine				
	(Tenex)	0.5–1	1–3		BID, TID, QID
	Atomoxetine	0.5/kg (<70 kg)	10–100	0.5–1.4	QAM, BID
	(Strattera)	40 (>70 kg)	40–100		QAM, BID
	Bupropion				
	(Wellbutrin SR)	100	100–300		BID, TID
	Imipramine				
	(Tofranil)	0.5/kg	25–100	0.5–3.5	BID, TID
	Desipramine				
	(Norpramin)	10–25	25–100		QD, BID, TID
	Pemoline				
	(Cylert)	37.5	37.5–112.5	0.5–2.5	QAM
	Naltrexon				
	(ReVia)	1/kg		1–2	QAM
Stereotypes & Obsessive–Compulsive Disorder	Clomipramine				
	(Anafranil)	25	25–200	<3	QHS
	Fluoxetine				
	(Prozac)	5–10	5–60		QAM, BID
	Fluvoxamine				
	(Luvox)	25	50–300		BID
	Paroxetine				
	(Paxil)	5–10	50–60		QAM
	Sertraline				
	(Zoloft)	25–50	25–200		QD
	Citalopram				
	(Celexa)	5	5–40		QAM, QPM
Tic Disorders	Halolperidol				
	(Haldol)	0.05/kg	0.5–6		BID, TID
	Pimozide				
	(Orap)	0.05/kg	1–10		QHS
	Clonidine	0.05	0.2–0.4		BID, TID, QID
	Risperidone				
	(Risperdal)	0.5–1	1–6		QD, BID

(Continued)

TABLE 12.1
(Continued)

Complication or Disorder	*Generic Name (Brand Name)*	*Suggested Initial Daily Dose (mg)*	*Suggested Later Daily Dosage*		*How to Take*[a]
			Range (mg)	*(mg/kg)*	
Major Depression	Imipramine	0.5/kg	25–100	0.5–3.5	BID, TID
	Fluoxetine	5–10	5–60		QAM, BID
	Fluvoxamine	25	50–300		BID
	Paroxetine	5–10	50–60		QAM
	Sertraline	25–50	25–200		QD
	Citalopram	5	5–40		QAM, QPM
	Escitalopram (Lexapro)	5–10	10–20		QAM, QPM
	Venlafaxine (Effexor)	25–50	50–375		BID, TID
	(Effexor XR)	25–50	<225		QD
	Nefazodone (Serzone)	50–100	300–600		BID
	Bupropion	100	100–300		BID, TID
Bipolar Affective Disorder	Lithium Carbonate (Eskalith or Lithobid)	600–900	900–1,200		BID, TID
	Divalproex Sodium (Depakote)	500–750		<60	BID, TID
	Valproic Acid (Depakene)	10–15/kg		<60	BID, TID
	Carbamazepine (Tegretol)	100–200	200–1000		BID, TID, QID
	Topiramate (Topamax)	1–3/kg	2.5–4.5		BID
Anxiety Disorders/ Panic Disorder	Buspiron (Buspar)	10–15	20–60		BID, TID
	Fluoxetine	5–10	5–60		QAM, BID
	Fluvoxamine	25	50–300		BID
	Paroxetine	5–10	5–60		QAM
	Sertraline	25–50	25–200		QD
Aggressiveness	Haloperidol	0.02–0.5/kg	0.5–16	0.1–0.5	QD, BID
	Risperidone	0.5–1	1–10		QD
	Olanzapine (Zyprexa)	5	15–20		QD
	Quetiapine (Seroquel)	25–50	300–400		BID, TID
	Trazodone (Desyrel)	50–70	200–400		BID, TID
	Lithium Carbonate	300–600	300–1,200		BID, TID
	Propranolol (Inderal)	30	50–960		BID
	Clonidine	0.001–0.002/kg	0.15–0.6		BID, TID
	Lorazepam (Ativan)	2–3	2–6		BID, TID

(Continued)

TABLE 12.1
(Continued)

Complication or Disorder	*Generic Name (Brand Name)*	*Suggested Initial Daily Dose (mg)*	*Suggested Later Daily Dosage*		*How to Take*[a]
			Range (mg)	*(mg/kg)*	
Self-Injury & QAM	Naltrexone	0.5/kg		0.5–2.0	
Withdrawal	Fluoxetine	5–10	5–60		QD, BID
Sleep Disorders	Clonidine	0.05	0.05–0.3		QHS
Insomnia	Melatonin	1	1–10		QHS
	Trazodone	25	25–250		QHS
	Imipramine	10	10–50		QHS
	Zolpidem tartrate (Ambien)	5	5–10		QHS
	Diphenhydramine (Benadryl)	25–50	25–500	2.0–5.0	QHS
	Hydroxyzine (Vistaril or Atarax)	0.6/kg	25–100	5	QHS
	Chloral Hydrate (Noctec)	500	500–1000		QHS
Night Terror	Diazepam (Valium)	1	1–20		QHS
Enuresis	Imipramine	0.5/kg	25–125	0.5–2.5	QHS
	Desmopressin	(Tablet) 0.2mg	02–0.6mg		
	(DDAVP)	(Nasal spray) 10μg	10–40μg		QHS
Schizophrenia	Risperidone	1	1–6		QD, BID
	Olanzapine	5	15–25		QD
	Quetiapine	25–50	300–400		BID, TID
	Clozapine (Clozaril)	12.5–25	100–700		QD, BID
	Aripiprazole (Abilif)	10–15	10–30		QD
	Ziprasidone (Geodon)	40	40–200		BID
	Haloperidol	0.02–0.5/kg	0.5–16	0.5	QD, BID
	Thiothixene (Navane)	6–10	20–30	0.3	BID
	Thioidazine (Mellaril)	25–50	50–800		TID
	Chlorpromazine (Thorazine)	75	100–2000		TID
Generalized Seizures	Phenobarbital	4–5/kg		3–6	BID, TID
Tonic-Clonic	Phenytoin				
(grand mal)	(Dilantin)	5/kg	<300	4–8	BID, TID
	Carbamazepine	200–400	400–1,200		TID, QID
	Primidone (Mysoline)	50–125	125–500		BID, TID, QID
Absence (Petit Mal)	Ethosuximide (Zarontin)	250–500	500–1,500	20	QD
	Valproic Acid	10–15/kg		30–60	BID, TID
	Clonazepam				

(Continued)

TABLE 12.1
(Continued)

Complication or Disorder	*Generic Name (Brand Name)*	*Suggested Initial Daily Dose (mg)*	*Suggested Later Daily Dosage*		*How to Take*[a]
			Range (mg)	*(mg/kg)*	
	(Klonopin)	0.01–0.03/kg		0.1–0.2	BID, TID
(Focal, Local)	Carbamazepine	200–400	400–1,200		TID, QID
	Primidone	50–125	125–500		BID, TID, QID
	Phenobarbital	4–5/kg		3–6	BID, TID
	Phenyltoin	5/kg		4–8	BID, TID
	Felbamate	1,200	1,200–3,600		BID, TID
	(Felbatol)	1,200	1,200–3,600		BID, TID
	Gabapentine (Neurontin)	900	900–3,600		TID
	Oxcarbazepine (Trileptal)	4–5/kg	900–1,800		BID
	Topiramate	1–3/kg		<4.5/kg	BID

[a]Dose recommendation is for children and adolescents.

[b]Abbreviations used: QD, once daily; BID, twice daily; TID, three times daily; QID, Four times daily; QAM, once daily taken in the morning; QPM, once daily taken in the late afternoon; QHS, once daily taken at bedtime.

side-effect profiles of the antipsychotic drugs. Both the effectiveness and the side effects of antipsychotics have been related to their selective affinities and interactions with the receptors of the neurotransmitter systems.

Antipsychotic medications, as their name suggests, act against psychotic symptoms. These medications cannot "cure" the illness, but they can take away many of the symptoms or make them milder. In some cases, they can shorten the course of the illness as well.

Traditional Neuroleptics

Traditional neuroleptics include six major classes: (a) phenothiazines, (b) thioxanthenes, (c) butyrophenones, (d) dihydro-indolones, (e) dibenzoxazepines, and (f) diphenylbutylpiperidines. In adults, neuroleptics are prescribed almost exclusively for the treatment of schizophrenia and other psychoses. In children, neuroleptics are used less specifically. That is, they have been used in reducing hyperactivity, stereotypies, tics, and aggressive behaviors. However, agreement over indications for the use of neuroleptics in children is not uniform (Rutter, 1985).

Among the traditional neuroleptics, butyrophenone (Haloperidol or Haldol), aliphatic phenothiazines (Chlorpromazine or Thorazine), and piperidine phenothiazines (Thioridazine or Mellaril) are the most frequently used medications. The bulk of the studies, however, have been done with Haloperidol (Campbell et al., 1982). Low-potency neuroleptics, such as Chlorpromazine, have little, if any, therapeutic effect because they yield

excessive sedation, even at low doses. On the other hand, Haloperidol, a high-potency neuroleptic, has demonstrated both short-term and long-term efficacy.

Butyrophenone (Haldol) is a dopaminergic blocking agent. Absorption of Haloperidol is rapid following both oral and intramuscular injection. Plasma elimination half-life (i.e., the particular time interval in which the plasma concentration falls to half its initial value) varies from 12 to 36 hours. Both high (0.05 mg/kg/day) and low (0.025 mg/kg/day) doses are effective in reducing behavioral symptoms in hyperactive and aggressive outpatients of normal intelligence (Campbell et al., 1984; Locascio et al., 1991).

Haloperidol, in doses ranging from 2 to 16 mg per day, was shown to be effective in reducing symptoms of acute schizophrenia in adolescents (Pool, Bloom, Mielke, Roniger, & Gallant, 1976).

Haloperidol has been systematically studied in autistic children. It has been reported that haloperidol, at doses ranging from 0.25 to 4.0 mg/day, is helpful in improving coordination, self-care, affect, and exploratory behavior; and in reducing stereotypies, withdrawal hyperactivity, and fidgetiness (Anderson et al., 1984; Campbell et al., 1978). Perry et al. (1989) reported that Haloperidol remained effective when given over a period of 6 months to 60 autistic children. Within age range of 2.3 to 8.2 years, Haloperidol was more effective in older than in younger children (Locascio et al., 1991).

At optimal doses, no untoward effects of Haloperidol are noted. Above optimal doses or during dose regulation, excessive sedation is most common, followed by acute dystonic reactions, Parkinson-like movements, and akathisia. Acute dystonic reactions usually occur within 72 hours of the first dose of Haloperidol; parkinsonian movements and akathisia usually occur during the first 3 months of treatment. Acute dystonic reactions can be treated with Benadryl orally or intramuscularly. Parkinsonian movements and akathisia can be ameliorated by the administration of antiparkinsonian agents.

Long-term side effects of Haloperidol include weight gain, withdrawal dyskinesia, and tardive dyskinesia. Withdrawal dyskinesia usually occurs within 2 weeks of Haloperidol, or other neuroleptics, withdrawal and lasts for 4 months or less. Tardive dyskinesia may be permanent; currently no satisfactory treatment is available. Perry et al. (1985) noted that a minimum of 3 months total cumulative exposure to the medication is necessary for the development of dyskinesia. Hence, it is recommended that the dosage increments be gradual and made on a regular basis. Furthermore, about every 4 to 6 months the medication should be discontinued in order to determine whether the child needs further medication treatment (Campbell, Adams, Perry, Spencer, & Overall, 1988).

In summary, Haloperidol has been demonstrated to be effective in the treatment of agitation, hyperactivity, aggression, stereotypic behaviors, motor and vocal tics, and affective lability. It is less effective in the treatment of

withdrawal behavior and in correcting impairment of cognition, communication, and social interaction. It has some risk of causing tardive dyskinesia.

Diphenylbutylpiperidine (Pimozide or Orap) is a potent dopamine antagonist. It is effective in reducing motor and vocal tics in Tourette disorder (Shapiro & Shapiro, 1984). After an oral dose of Pimozide, peak serum levels occur 6 to 8 hours. The mean serum elimination half-life in schizophrenic patients is approximately 55 hours. However, the correlation between plasma levels and clinical findings is not clear. In the treatment of Tourette disorder, the mean daily dose is about 7 mg and the maximum dose was 10 mg/day.

In a study that compared Haloperidol (0.75–6.75 mg/day) and Pimozide (1–4 mg/day) in 87 autistic children and adolescents, Pimozide was found to be superior to both Haloperidol and placebo on behavioral ratings, and on global ratings the two drugs were equally superior to placebo (Naruse et al., 1982). Pimozide was also effective in reducing hypoactivity in autistic children (Ernst et al., 1992).

Side effects of Pimozide include sedation, parkinsonian symptoms, and T-wave change of EKGs (Shapiro & Shapiro, 1984). It is recommended that pretreatment laboratory studies should include EKGs, vital signs, blood count, and liver function profile. These measures should be monitored periodically (Campbell, Cohen, Perry, & Small, 1989).

Atypical Neuroleptics

Risperidone (Risperdal) is a newer antipsychotic agent belonging to a new chemical class, the benzisoxazole derivatives. It is a potent dopamine Type 2 (D2) and serotonin Type 2 ($5\text{-}HT_2$) receptor antagonist. It has efficacy against both the positive and the negative symptoms of schizophrenia and has significant advantages over both the conventional dopamine-blocking neuroleptics and the atypical antipsychotic clozapine (Huttunen, 1995). Risperidone has also been reported to be effective in treating tic disorders including Tourette disorder (Bruun & Budman, 1996), obsessive–compulsive disorder (McDougle, Fleischman, et al., 1995; McDougle, Kresch, et al., 1995), and pervasive developmental disorder (Purdon, Lit, Labelle, & Jones, 1994). It has also been reported to reduce repetitive behavior, aggression, anxiety or nervousness, depression, irritability, self-injury, and overall behavioral symptoms (Findling, Maxwell, & Wiznitzer, 1997; Fisman & Steele, 1996; Horrigan & Barnhill, 1997; Malone, Maislin, Choudhury, Gifford, & Delaney, 2002; McCracken et al., 2002; McDougle et al., 1998; Perry, Pataki, Munoz-Silva, Armenteros, & Silva, 1997; Posey, Walsh, Wilson, & McDougle, 1999; Purdon et al., 1994; Zuddas, Di Martino, Muglia, & Cianchetti, 2000). The present author's preliminary experience with risperidone seems to suggest efficacy in reducing the frequency and intensity of temper outbursts and

aggression in children and adolescents with autism. Further larger studies are needed to determine whether risperidone has more advantages than do other conventional psychotherapeutic medications.

Although it is believed that risperidone has a low tendency to produce EPS, withdrawal dyskinesias was noted (Malone et al., 2002). Weight gain seems to be common (Findling, Maxwell, & Wiznitzer, 1997; Horrigan & Barnhill 1997; Malone et al., McCracken et al., 2002; Zuddas et al., 2000). The rate of increase lessened over a period of time, and after drug withdrawal, considerable weight loss was observed in the patients who had previously shown the most significant increase of weight (Zuddas et al.). It can also cause side effects of somnolence, increased dream activity, anxiety, dry mouth, dizziness, constipation, micturition disturbances, nausea, dyspepsia, rhinitis, rash, and tachycardia.

Quetiapine fumarate (Seroquel) is an antagonist at multiple neurotransmitter receptors in the brain: serotonin-5-HT_{1A}, 5-HT_2, dopamines D_1 and D_2, histamine H_1, and adrenergic α_1 and α_2 receptors. In an open-label quentiapine treatment in six autistic children, Martin et al. (1999) reported that there was no significant improvement based on the Clinical Global Impression Scale (CGI) and that quetiapine was poorly tolerated and associated with serious side effects.

Olanzapine (Zyprexa) is a selective monoaminergic antagonist with high-affinity binding to the following receptors, serotonin 5-$HT_{2A/2C}$, dopamine D_{1-4}, muscarinic M_{1-5}, histamine H_1, and adrenergic receptor. Five of six children treated with olanzapine showed CGI improvement (Malone, Cater, Sheikh, Choudhury, & Delaney, 2001). Weight gain is common with olanzapine treatment.

Zaiprasidone (Geodon) functioned as an antagonist at the D_2, 5-HT_{2A}, and 5-HT_{1D} receptors, and as an agonist at the 5-HT_{1A} receptor. Zaiprasidone inhibited synaptic reuptake of serotonin and norepinephrine. Twelve patients with autistic or pervasive developmental disorder not otherwise specified were treated with zaiprasidone for at least 6 weeks. Six (50%) of the 12 patients were considered responders based on a CGI scale. It appears that zaiprasidone may have the potential for improving symptoms of aggression, agitation, and irritability. The most common side effect was transient sedation. Significant weight gain was not observed in the short-term open-label trial (McDougle, Kem, & Posey, 2002).

Stimulants

The stimulants are referred to as such because of their ability to activate the level of activity, arousal, or alertness of the CNS; to reduce fatigue; and to elevate mood in most people. Medications in this category include the amphetamines (Dexedrine, Adderall), methylphenidates (Ritalin,

Concerta), magnesium pemoline (Cylert), cocaine, caffeine, and phenylpropanolamine (a common ingredient in over-the-counter appetite suppressors). The amphetamines and methylphenidates are structurally similar to brain catecholamines and are called sympathomimetic compounds because they may mimic the actions of these brain neurotransmitters. The other (noncatecholaminergic) stimulants (e.g., caffeine) will not be discussed in this chapter because they have not been found to be nearly as effective as the catecholaminergic stimulants and cannot be recommended for medical use.

The amphetamines and methylphenidates may enhance CNS catecholamine (norepinephrine and dopamine) release from sympathetic nerve terminals and inhibition of reuptake in the caudate nucleus. Absorption is fairly rapid following oral administration of both amphetamines and methylphenidate. Peak plasma concentrations are usually observed 1 to 3 hours after an oral dose. The mean half-life of amphetamines is about 6 hours. There is some correlation of peak concentration of dextroamphetamine with improvement in behavior variables in children. The half-life of methylphenidate is 2 to 7 hours. A sizeable number of studies of the stimulants in hyperactive- and behavior-disordered children have been published by many medical centers. It is now generally accepted that stimulants are efficacious in decreasing restless, impulsive behaviors and improving attention span in these children. However, there is a relative lack of effect of stimulants on academic achievement and on interpersonal functioning.

The use of stimulants in autism has not received extensive evaluation. Quintana et al. (1995) reported modest but statistically significant improvement on methylphenidate in 10 autistic children. Handen, Johnson, and Lubetsky (2000) reported that 8 of 13 autistic children showed positive response on methylphenidate, based on a minimum 50% decrease on the Conners Hyperactivity Index (CHI). Stimulants are frequently reported to exacerbate irritability, insomnia, and aggression in clinical population (Posey & McDougle, 2000).

Stimulants may be considered in a higher functioning autistic child without seizure or other neurological disorders, but in whom short attention span, distractibility, impulsivity, and excitability are significant symptoms (Tsai, 2001). To determine the role of stimulants in autism, a well-designed study is needed.

Short-term side effects of stimulants include decreased appetite, insomnia, anxiousness, irritability, proneness to crying, stomachaches, and headaches. Most of the side effects are usually of mild severity and diminish within 1 to 2 weeks of beginning medication. All short-term side effects disappear upon cessation of stimulant treatment.

A number of cases of irreversible Tourette syndrome have been reported as associated to stimulant treatment. Current evidence implies that where

Tourette syndrome emerges in association with stimulant treatment, it may simply be coincidental in that the children were likely to have developed the disorder independent of their stimulant treatment. It has been estimated that less than 1% of ADHD children treated with stimulants will develop a tic disorder and that in about 10% of the cases stimulants may exacerbate preexisting tics. If children without prior history of tic disorders develop tics during stimulant treatment, the stimulant should be discontinued immediately. The tics usually subside within 7 to 10 days. Although the vast majority of such reactions subside once the stimulant is discontinued, there are a few cases in the literature where the tics apparently did not diminish in frequency and severity following termination of treatments.

Stimulants at higher doses can produce stereotyped behavior and these are occasionally seen in children. Stimulants may also increase choreiform movements and self-directed behavior, such as lip licking, lip biting, and light picking of the fingertips (not the nails).

Stimulants can produce temporary symptoms of psychosis (e.g., thought disorganization, press of speech, tactile hallucinations, extreme anxiety, hyperacusis) at very high doses, or even at smaller doses in a rare child. Such reactions are quite uncommon.

The side effects of using stimulants over several years with children and adolescents have not been well studied. Nevertheless, from the data presently available, there is no reason to suggest that chronic stimulant use may cause any significant disadvantages.

Antidepressants

Antidepressants are used in severe, unremitting cases of depression, generally for those depressions for which there appear to be no clear causal events. Antidepressants, however, can also be helpful for some milder depressions. Antidepressants take away or reduce the symptoms of depression and help the depressed person feel the way they did before they became depressed. Antidepressants are also used for disorders characterized principally by anxiety. They can block the symptoms of panic, including rapid heartbeat, terror, dizziness, chest pains, nausea, and breathing problems. They can also be used to treat some phobias and obsessive–compulsive symptoms.

There are a number of antidepressant medications available. They differ in their side effects and, to some extent, in their level of effectiveness. The oldest types are MAOIs and tricyclic antidepressants (TCAs; named for their chemical structure with a three-ring nucleus). The TCAs include: amitripryline (Elavil), desipramine (Norpramin), doxepin (Sinequan), imipramine (Tofranil), nortriptyline (Pamelor or Aventyl), protriptyline (Vivatil), and trimipramine (Surmontil). There are a number of more recent

antidepressants that have various nontricyclic configurations. These include the SRIs such as fluoxetine (Prozac), fluvoxamine (Luvox), sertraline (Zoloft), paroxetine (Paxil), citalopram (Celexa), escitalopram (Lexapro), venlafaxine (Effexor), and SERZONE nefazodone (Serzon). Also included in the category of newer drugs are mirtazapine (Remeron), bupropion (Wellbutrin), and trazadone (Desyrel). Bupropion and trazadone are not chemically related to TCAs or SRIs. The newer antidepressants are generally about as effective as the TCAs, though side effects and time of onset of action may differ.

MAOIs may be helpful in depression that shows atypical features such as hypersomnia and overeating. However, physicians who treat individuals with autistm rarely prescribe MAOIs because their use imposes certain dietary restrictions. Hence, details of MAOIs are not included in this chapter.

The primary cellular actions of the antidepressants are on the monobreak amine neurotransmitter system. The monoamine neurotransmitters include acetylcholine, norepinephrine, serotonin, and dopamine. Generally, the antidepressants act by influencing the metabolism or reuptake of these neurotransmitters, which results in functionally increased levels of available neurotransmitters.

Fluoxetine, a 5-HT reuptake blocker, has been reported not only to reduce overall autistic symptoms (Buchsbaum et al., 2001; Cook et al., 1992; DeLong, Teague, & McSwain-Kamran, 1998; Fatemi, Realmuto, Khan, & Thuras, 1998) but also to induce significant side effects, including restlessness, hyperactivity, agitation, vivid dreams, decreased appetite, and insomnia (Cook et al., 1992; Fatemi et al., 1998).

Fluvoxamine, another 5-HT reuptake blocker, was reported as more effective than placebo in a short-term treatment of symptoms of autistic (i.e., social relatedness, repetitive thoughts and behavior, maladaptive behavior, and aggression) in 15 adults (McDougle et al., 1996).

Sertralin, another 5-HT reuptake blocker, was reported as effective in reducing self-injury and aggression in mentally retarded autistic patients (Hellings, Kelley, Gabrielli, Kilgore, & Shah, 1996), and in transition-associated anxiety and agitation in autistic children (Steingard, Zimnitzky, DeMaso, Mauman, & Bucci, 1997).

Trazodone's efficacy in the treatment of depression in children and adolescents has not been investigated. However, it has been recommended for the treatment of sleep disturbance and aggression in persons with developmental disabilities (Gualtieri, 1991). Usual side effects of trazodone include drowsiness, dizziness and lightheadedness, dry mouth, blurred vision, fatigue, headache, nervousness, nausea and vomiting, constipation. One potentially serious side effect of trazodone is priapism (prolonged erection of penile) which may require surgical treatment.

Low dosage of venlafaxine, a potent inhibitor of neuronal serotonin and norepinephrine reuptake, was reported as effective in six subjects with autistic. Improvement was noted in repetitive behaviors and restricted interests, social deficits, communication and language function, inattention, and hyperactivity (Hollander, Kaplan, Cartwright, & Reichman, 2000).

Treatment effects of antidepressants generally will not begin to show immediately. With most of these medications, it will take from 1 to 3 weeks before changes begin to occur. Some symptoms diminish early in treatment; others, later. Early responses include relief of both anxiety and insomnia. Even though the individual may state that the depression has not lifted, there is usually increased energy and less preoccupation with somatic concerns in the first several weeks of therapy. Mood and sexual dysfunction are often the last problems to be relieved.

Dosage of antidepressants varies, depending on the type of drug, the person's body chemistry, age, and, sometimes, body weight. Dosages are generally started low and raised gradually over time until the desired effect is reached without the appearance of troublesome side effects. The lag in clinical response may be as much as several weeks; however, the side effects of these medications limit the clinician's ability to increase the dosage rapidly. The lag time is apparently related to delays in achieving therapeutic blood levels and the interval required to affect neurotransmitter systems. The drug should be tried for several weeks at maximum doses before it is considered a failure.

Except for some early adjustments, it is not necessary to use divided doses of antidepressants: A single dose at bedtime is adequate (particularly when the clinician takes advantage of the sedative side effects to help treat associated insomnia). The bedtime dose helps achieve compliance, because people tend to take drugs at bedtime and not during the day. Maintenance dosages of tricyclic antidepressants are usually one half to one third the amount needed by the individual for treatment of an acute episode. The dosage is maintained for several months, and thereafter the medication is given in the lowest effective dose for as long as the depression continues. This involves a gradual downward adjustment of the dosage until the individual requires no medication. A process usually takes 6 or more months from the start of the depression.

There are a number of possible side effects with antidepressants that vary, depending on the medication. Side effects of tricyclics include dry mouth, nausea, anorexia, constipation, lethargy, tremors, sweating, insomnia, irritability, tachycardia, ECG changes (e.g., T-wave abnormalities, prolongation of P–R interval, widening of QRS interval, ventricular extrasystoles, bundle branch block) and hypotension. When tricyclics are used with amphetamines, hypertensive crises may develop. When tricyclics are used with

Ritalin, the serum level of the tricyclic may increase. Common adverse effects of SRIs include nausea, nervousness, headache, insomnia, dry mouth, constipation, urinary retention, and urticaria or other skin rash. Fluoxetine may rarely precipitate seizures in patients with convulsive disorders.

Tricyclic Antiobsessional Antidepressants

Clomipramine (CMI or Anafranil) is an antiobsessional drug that belongs to the class of tricyclic antidepressants. It is presumed to influence obsessive and compulsive behaviors through its effects on serotonergic neuronal transmission due to its relatively selective capacity to inhibit the reuptake of serotonin. After a single 50-mg oral dose, maximum plasma concentration of CMI occurs within 2 to 6 hours. After a 150-mg oral dose, the half-lives of CMI range from 19 hours to 37 hours.

The effectiveness of CMI for the treatment of OCD was demonstrated in multicenter, placebo-controlled, parallel-group studies, including 10-week studies in adults, as well as in children and adolescents 10 to 17 years of age (DeVeaugh-Geiss, Landau, & Katz, 1989; Leonard et al., 1989). The maximum daily dosage is 250 mg for most adults and 3 mg/kg for all children and adolescents.

Gordon, State, Nelson, Hamburger, and Rapoport (1993) reported that CMI significantly reduced stereotypies, compulsive symptoms, withdrawal, and hyperactivity in autistic subjects. However, a recent study of seven young autistic children reported that CMI was not therapeutic and was associated with serious untoward effects (Sanchez et al., 1996). Larger-sample size studies are warranted to confirm the positive results.

The most common side effects of CMI are dry mouth, somnolence, tremor, dizziness, constipation, and ejaculatory failure. Lowering the dosage often reduces side effects when they occur, usually without loss of therapeutic benefit. CMI may lower seizure threshold and induce seizure attacks.

Antiobsessive–Compulsive Medications

There are two groups of medications that have been noted to be effective in the treatment of OCD. They are (a) tricyclic antiobsessional antidepressants (Anafranil) and (b) SRIs (e.g., Prozac, Luvox, Zoloft, Paxil, Celexa). These medications have been discussed.

Antianxiety Medications

Antianxiety medications are those drugs whose primary purpose is to relieve anxiety arising in normal life or in nonpsychotic psychiatric disorders such as those classified in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) or in the *International Classification of Diseases* (ICD) as anxiety,

adjustment, somatoform disorders. This somewhat arbitrary definition distinguishes antianxiety medications from other medications such as antipsychotics or antidepressants that are also used in the treatment of anxiety but developed primarily for psychotic or severe mood disorders.

The following are the frequently prescribed antianxiety medications (benzodiazepines [BZDs]): alprazolam (Xanax), chlordiazepoxide (Librium or Librax), diazepam (Valium), lorazepam (Ativan), clonazepam (Klonopin), triazolam (Halcion), flurazepam (Dalmane). The properties of these BZDs are quite similar to those of the sedative–hypnotics. The various sedative effects differ mainly in milligram potency, dose–response curves, and onset and duration of action. All are general depressants of brain function and decrease anxiety except triazolam and flurazepam, which are marketed for sleep problems. To varying degrees, all have the potential for dependency with tolerance and severe withdrawal symptoms. They are additive and have cross tolerance and cross dependence. On the whole, low-potency or long-acting medications like diazepam should be preferred because their adverse effects have been far better researched. Also, the high-potency or short-acting medications tend to cause more problems of dependence, rebound, and withdrawals. In the case of sleep disturbances, however, a short-acting drug may be preferable, particularly if it is to be given for only a very few days.

BZDs differ in duration of action in different individuals. They may be taken two or three times a day, or sometimes only once a day. Dosage is generally started at a low level and gradually raised until symptoms are diminished or removed. The dosage will vary a great deal depending on the symptoms and the individual's body chemistry. In general, it begins with a low dosage, 25%, and (except in emergencies or anticipated short-term use) is incremented slowly over intervals of several days (5 to 7) to allow time for accumulation in fat stores and the production of active metabolites. Often BZDs may help for a time and then the effect seems to wear off and an increased dosage is needed to achieve the same effect. However, BZDs should not be used in excess of 4 months and shorter periods are desirable. As ever in medicine, the objective is to give the smallest therapeutic dosage for the shortest time, but this is particularly important with anxiolytics because both duration and dosage are correlated with adverse effects.

Antianxiety medications have not been well studied in children and adolescents and thus have no established role or dosage. Also, because children and adolescents are active learners, adolescents are often exposed to pressures to abuse drugs, and there are pharmacological similarities and cross-tolerance with alcohol, the anxiolytics, particularly BZDs, and are not medications to be prescribed lightly.

A newer category of nonsedating, nonaddictive antianxiety medication (e.g., buspirone [BuSpar]) has recently been introduced. Its molecular

structure is uniquely different from the rest of the anxiolytics. It also lacks their hypnotic, anticonvulsant, and muscle-relaxant properties. Thus, it differs from the BZDs in that motor skills are not impaired. It does not appear to act synergistically with alcohol, and it is likely to possess a much lower potential than the BZDs for abuse, dependence, and withdrawal syndrome. Despite having no FDA-approved indications for use with persons younger than 18 years of age, the use of buspirone with children and adolescents is of great interest to child psychiatrists because of its minimal sedation and low potential for abuse.

Side effects of benzodiazepines include drowsiness, loss of coordination, fatigue, and mental slowing or confusion. Other side effects are rare. With benzodiazepines, there is a potential for development of tolerance and dependence as well as the possibility of abuse and withdrawal reactions.

Sedative-Hypnotics (Sometimes Referred to as Depressants)

Sedative–hypnotics sedate, calm, or relax most individuals at low doses; and at somewhat higher doses, induce sleep in most individuals. It should be pointed out that the hypnotic effect of the medication-induced sleep is very different from the phenomena associated with hypnosis. The confusion comes about because it was once believed that hypnosis induced a sleep-like trance. However, we now know that hypnotized people are very much awake. Many medications in this class are effective in reducing seizure activity and may be termed *anticonvulsants.* They may also be used as muscle relaxants, although muscle relaxation is secondary to their effects on the CNS. The following are frequently used sedative–hypnotics: chloral hydrate (Aquachloral); hydroxyzine (Atarax or Vistaril); secobarbital, phenobarbital, and pentobarbital (Barbiturates); diphenhydramine (Benadryl); and promethazine (Phenergan).

The highly addicting medications with a narrow margin of safety such as glutethimide (Doriden), methaqualone (Quaalude), and the barbiturates (with the exception of phenobarbital) should be avoided.

Opiate Antagonists

There are medications with relatively pure opiate-blocking properties, which act by competitive binding at opioid receptors. They can reduce the subjective effects of opiate narcotics and help to reverse respiratory and cardiovascular depression caused by overdose with opiates. The opiate blockers have been used to treat individuals with self-injury, social withdrawal, and ADHD. There are two frequently used opiate blockers: naltrexone (Trexon) and naloxone (Narcano).

Naltrexone has been reported to have positive effects on hyperactivity, social relatedness, and self-injury (Campbell et al., 1989, 1993; Herman et al.,

1987, 1991; Kolmen, Feldman, Handen, & Janosky, 1995, 1997). The therapeutic changes occurred at doses of 0.5 to 2.0 mg/kg/day. When the effect of naltrexone on self-injurious behavior (SIB) was tested in a larger sample (i.e., 36 autistic children), the naltrexone- and placebo-treated groups did not differ significantly regarding decline of SIB (Campbell, Magee, Locascio, Lynch, & Anderson, 1990), though naltrexone showed some effect on reducing hyperactivity in the autistic group (Campbell et al., 1993). In a double-blind placebo-controlled crossover study in 23 autistic children, aged 3 to 7 years, with a mean daily dosage of 1 mg/kg of naltrexone for 4 weeks, the teachers reported a decrease in hyperactivity and irritability, but effects on social and stereotypic behavior could not be demonstrated (Willemsen-Swinkels, Buitelaar, Weijnen, & van Engeland, 1995; Willemsen-Swinkels, Buitelaar, & van Engeland, 1996). Other investigators did not find the previously reported effects (Feldman, Kolmen, & Gonzaga, 1999; Gillberg, 1995; Zingarelli et al., 1992). Willemsen-Swinkels, Buitelaar, Nijhof, and van Engeland, (1995) reported increased incidence of stereotyped behavior by naltrexone treatment.

It appears that there are not yet sufficient clinical data to suggest the use of opiate antagonists in the treatment of autism. Nevertheless, naltrexone merits further study in autistic children with moderate to severe self-injury and those with severe hyperactivity who do not respond to other medications commonly used for managing hyperactivity.

Alpha (α)-Adrenergic Agonists

The α-adrenergic receptor agonists stimulate presynaptic autoreceptors, leading to the release of noradrenaline, lowering of blood serotonin, and increased dopamine turnover. They are used primarily as antihypertensive agents. However, they may be helpful in reducing overexcitability, overstimulation, and impulsivity as seen in ADHD. They may also be useful in the treatments of Tourette disorder (Leckman et al, 1982); sleep problems, aggression, stuttering, and anxiety disorders. They are two frequently used α-adrenergic agonists: clonidine (Catapres) and guanfacine (Tenex).

Clonidine (Catapres). It appears that clonidine stimulates α-adrenoreceptors in the brain stem, resulting in reduced sympathetic outflow from the CNS. After an oral dose, the plasma level of clonidine peaks in approximately 3 to 5 hours and the plasma half-life ranges from 12 to 16 hours. In doses of 0.6 to 2.0 mg per day, clonidine seems to be helpful in decreasing compulsive behaviors, as well as aggressiveness, hyperactivity, and attentional difficulties (Jaselskis, Cook, & Leventhal, 1990). It is less effective in reducing tics as compared with Haloperidol and Pimozide. However, it has fewer side effects than Haloperidol.

Most side effects of clonidine are mild and tend to diminish with continued therapy. Clonidine, however, can cause significant drowsiness and decreased activity (Fankhauser, Karumanchi, German, Yates, & Karumanchi, 1992; Jaselskis et al., 1992). Other common side effects include dry mouth, drowsiness, dizziness, constipation, and sedation. Further larger studies are warranted to determine whether clonidine is also effective in compulsive and aggressive behaviors.

Guanfacine (Tenex) is another 2-adrenoceptor agonist with longer excretion half-life, decreased sedative side effects, and more selective binding profiles than those of clonidine. It has been reported to show effectiveness in treating children with ADHD (Hunt, Arnsten, & Asbell, 1995) and in children with both ADHD and Tourette disorder (TD) (Chappell et al., 1995). Further larger studies are warranted to determine the efficacy of guanfacine in the treatment of ADHD and Tourette disorder.

The side effects of guanfacine are similar to those of other medications of the 2-adrenoceptor agonist class: dry mouth, sedation, weakness, dizziness, constipation, and impotence. Although the side effects are common, most are mild and tend to disappear on continued dosing.

Beta (β)-Adrenergic Blockers (β-Blockers)

β-Adrenergic receptors are activated by adrenergic sympathetic nervous transmission and by endocrine catacholamine such as noradrenaline. β-Blockers can work on both β_1 and β_2 receptors. The former receptors are found mainly in the heart and brain, whereas the latter are implicated in the functioning of vascular, bronchial, and gastrointestinal organs. β_1-Blockers tend to decrease heart rate, cardiac output, blood pressure, and maximal exercise tolerance. They also have an antiarrhythmic effect on the heart. β_2-Blockers block the action of sympathomimetic amines, leading to increase in airway resistance, which is potentially dangerous in asthma.

Propranolol (Inderal) is a β-adrenergic receptor blocker that tends to decrease heart rate, cardiac output, blood pressure, and maximal exercise tolerance. It also has an antiarrhythmic effect on the heart. It has been reported as being effective in reducing severe and treatment-resistant aggressiveness directed against others or oneself. These reports, however, are based on uncontrolled trials or case reports involving nonautistic subjects. Furthermore, the patients were diagnostically heterogeneous (Campbell et al., 1989). Further studies are needed to determine the role of β-blockers in the autistic population.

Side effects of propranolol include Raynaud's phenomenon, bradycardia, bronchoconstriction, depression and dysphoria, hallucination, hypotension, vomiting and nausea, diarrhea, insomnia, nightmares, dizziness, and hypoglycemia.

Antimanics

Antimanics are most useful in the treatment of manic symptoms, but they may also be useful in the treatment of other symptoms that appear to be only tangentially related to mood. Because these medications are generally successful in decreasing rapid mood swings, from mania to depression, they are also sometimes referred to as *mood stabilizers*. Although the antipsychotics are quite effective in reducing manic symptoms and are often used for the initial treatment of mania, they are generally not used for chronic treatment in affective disorders because of their potentially severe side effects. There has been no study of these medications in individuals with both ASD and mania because the latter disorder has rarely, if at all, been reported in individuals with ASD.

The medication of choice is generally a lithium salt, such as lithium carbonate (Lithobid or Eskalith). Alternatives to lithium are divalproex sodium (Depakote), valproic acid (Depakene), carbamazepin (Tegretal), clonazapam (Klonopin), and erapamil (Calan).

Lithium is a monovalent cation and the lightest alkali metal. In adult literature, lithium has a mood-reducing effect in manic disorder. It may also reduce aggressiveness and hyperactivity in some individuals. Its exact mechanism of action in manic disorder is not fully known. Pharmacokinetic data of lithium in children are not available. In adults, absorption is rapid from the gastrointestinal tract with peak blood concentration at 2 to 4 hours after a single oral dose. The half-life of lithium elimination is 24 hours and the onset of effect is 6 to 10 days.

The role of lithium in children is unclear. Only a few controlled studies are available. It appears that lithium is effective in reducing aggressive behavior in children of normal intelligence diagnosed as having conduct disorder. The therapeutic doses ranged from 500 to 2,000 mg/day with plasma levels ranging from 0.32 to 1.51 mEq/L (Campbell et al., 1989).

There are uncontrolled studies that suggest lithium may have an antiaggressive effect in children with mental retardation. To confirm this suggestion, controlled studies are needed.

Lithium has not been systematically studied in any autistic population However, lithium should be considered in the treatment of autistic individuals who have clear bipolar affective illness, or in autistic persons with severe aggressive or self-injurious behavior but who fail to respond to other antiaggressive medications.

The most common side effects of lithium include stomachache, anorexia, nausea, vomiting, diarrhea, tremor of hands, headache, and weight gain. Leukocytosis with lymphocytopenia, a decrease in thyroxine iodine, urinary frequency, and polyuria have also been reported. These side effects are usually minimal within the therapeutic range and often disappear after several weeks of use.

Anticholinergics

Anticholinergic drugs (e.g., benztropine [Cogentine], trihexyphenidyl [Artane]) are used primarily to reverse the extrapyramidal side effects of the conventional antipsychotics. As such, the drug interaction is beneficial.

Anticonvulsants

The anticonvulsants of particular relevance are Phenobarbital and related barbiturates: Phenytoin (Dilantin), Carbamazepine (Tegretal), Ethosuximide (Zarontin), Valproate (Depakene), and Clonazepam (Clonopin). These anticonvulsants may act through two mechanisms to achieve their effect: direct modification of neuronal membrane function and alteration of neurotransmission. Anticonvulsants have been used to treat autistic symptoms. Hollander, Dolgoff-Kaspar, Cartwright, Rawitt, and Novotny (2001) reported that 10 of 14 autistic patients on divalproex sodium were rated as having sustained response to treatment. It appeared that the responders were those who had associated features of affective instability, impulsivity, and aggression as well as those with a history of EEG abnormalities or seizures.

The following anticonvulsants are the most commonly used in controlling various types of seizure disorders:

Phenobarbital (Luminal) is absorbed slowly from the gastrointestinal tract. The serum half-life of phenobarbital is about 96 hours. In treating grand mal seizures, the drug is effective at levels of 10 to 30 μg/ml, which can be achieved by an oral dosage of about 4 to 5 mg/kg/day, given in two divided doses. Toxic levels of phenobarbital vary from one individual to another. However, no permanent sedation has been seen with levels below 35 μg/ml.

Phenobarbital and other barbiturate anticonvulsants may cause hyperactivity or drowsiness. These anticonvulsants may also cause initial impairment in cognitive functions that disappear after the first year of therapy (Hellström & Barlach-Christoffersen, 1980).

Phenytoin (Dilantin) is slowly absorbed from the gastrointestinal tract. At a dose of 4 to 6 mg/kg/day, equilibrium levels in the blood are established between 7 and 10 days after initiation of therapy. The serum half-life of phenytoin is 13 to 46 hours. The average effective dose of phenytoin in children is 5 to 10 mg/kg/day, given at approximately 8-hour intervals. Clinically, phenytoin is effective in controlling tonic–clonic (grand mal) seizures and the therapeutic levels range from 10 to 20 μg/ml. However, it has lost considerable favor as a long-term anticonvulsant for use in children because of the wide variability in its absorption, the effect of other anticonvulsants, and the relatively high incidence of side effects.

About 2% to 5% of patients receiving phenytoin develop fever, a morbilliform rash, and lymphadenopathy within 2 weeks of the start of therapy and with blood levels in the therapeutic range. After discontinuation of the medication, the symptoms clear (Dawson, 1973). At therapeutic level, prolonged phenytoin therapy causes gum hyperplasia, megaloblastic anemia, lower serum folate concentration, disturbed vitamin D metabolism resulting in hypocalcemic rickets, decreased serum calcium and phosphorus, increased alkaline phosphatase (Crosley, Chee, & Berman, 1975), and peripheral neuropathy. At toxic level, phenytoin may cause sedation, impairment of motor coordination and performance (e.g., ataxia), and negative effects on memory and learning, irreversible degeneration of the cerebellar Purkinje cells (Kokenge, Kutt, & McDowell, 1965), and aggravation of underlying behavior disorder.

Carbamazepine (Tegretol) is chemically unrelated to any of the other major anticonvulsants. Individuals with psychomotor and grand mal seizures are most likely to benefit from the drug. Steady-state blood level of carbamazepine is established between 5 and 10 days. The serum half-life of carbamazepine is 8 to 20 hours. The starting dosage in children aged 6 to 12 is 20 to 25 mg/kg/day (200 mg/day), and maximum dosage for effective seizure control in that age range is about 800 mg/day. Optimal therapeutic levels are between 4 and 12 μg/ml.

The most common side effect of carbamazepine is diplopia which may disappear spontaneously or after reduction of drug dosage (Lesser, Pippenger, Luders, & Dinner, 1984). Other side effects include rashes, hyponatremia, hepatic dysfunction, and leukopenia. Carbamazepine may also cause hyperactivity, irritability, insomnia (Rivinius, 1982), memory impairment, assaultive behavior, agitation, and motor and phonic tics (Evans & Gualtieri, 1985). Such effects may occur at low doses and at low blood levels of such anticonvulsants.

Primidone (Mysoline) is used to control partial seizures, myoclonic seizures, and secondarily generalized seizures. Common side effects include somnolence, ataxia, rash, and depression.

Ethosuximide (Zarontine) is the most effective medication for treatment of absence (petit mal) seizures. Starting doses for children are 250 mg twice daily or 20 mg/kg/day. Steady-state blood level is reached between 5 and 8 days. The serum half-life of ethosuximide is about 30 hours. Optimal therapeutic plasma levels are between 40 and 100 μg/ml.

Side effects of ethosuximide are rare. They include gastrointestinal upsets, skin rashes, headaches, and occasional reversible leucopenia.

Valproic acid (VPA) or Valproate (Depakene, Depakote) is highly effective in controlling minor motor, grand mal, petit mal, and simple partial seizures. Starting dosages for children are 15 to 20 mg/kg/day given two to three times a day. The dosage is increased at weekly intervals to a level

that provides seizure control, usually in the range of 20 to 70 mg/kg/day. Steady-state blood level is reached in about 4 days. The serum half-life of VPA is short, about 6 to 15 hours. However, the correlation between blood levels and therapeutic effects or adverse reactions has not been established.

Side effects of VPA include gastrointestinal upsets, increased appetite and weight gain, hepatic dysfunction, sedation, tremor, and asterixis. These side effects tend to develop when the patients are receiving polytherapy.

Clonazepam (Clonopine, Klonopin) is an effective anticonvulsant for most types of minor motor seizures, particularly akinetic and atypical petit mal seizures. It appears that clonazepam is most effective when given in conjunction with phenobarbital or other anticonvulsants. The drug is given in gradually increasing dosages beginning at 0.05 mg/kg/day in three or four divided doses, and increased by 0.05 mg/kg every fifth to seventh day until seizures are controlled or until a dosage of 0.25 mg/kg is reached. Thereafter, the dosage is raised more slowly to 0.5 mg/kg if needed, or until side effects are encountered. In general, it may take 14 days to reach the steady-state blood level. The serum half-life of clonazepam is 22 to 33 hours. At present, the relationship of blood levels to therapeutic and toxic effects of clonazepam is unclear.

Clonazepam may cause sedation, memory impairment, depression, excessive weight gain, ataxia, dysarthria, and paradoxical excitement or disinhibition (Rivinius, 1982).

Newer Anticonvulsants

Gabapentin (Neurontin) is a new anticonvulsant approved to be used as an add-on treatment in adults for partial seizures and secondary generalized seizures. Common dose-related side effects include dizziness, ataxia, somnolence, and weight gain. Idiosyncratic adverse effect is skin rash.

Felbamate (Felbatol) is a relatively new anticonvulsant for the treatment of partial seizures, generalized seizures, secondary generalized seizures, absence seizures, and myoclonic seizures. Common dose-related adverse effects are anorexia, weight loss, headaches, and insomnia. Idiosyncratic side effects include aplastic anemia and liver failure. Use of felbamate is restricted by a FDA advisory because of the risk of idiosyncratic side effects.

Lamotrigine (Lamictal) is approved for (a) adjunctive treatment for partial seizures in adults 16 years and over, (b) adjunctive treatment of generalized seizures in Lennox–Gastaut syndrome in adult and pediatric patients 2 years of age and older, (c) monotherapy for partial seizures in adults 16 years of age and older following withdrawal of concomitantly used enzyme-inducing anticonvulsant medication, and (d) monotherapy for epilepsy treatment following withdrawal of concomitantly used anticonvulsant medications. It has also bas been used by clinicians to treat

(a) generalized seizures—absence, myoclonic, tonic–clonic; (b) patients with learning disability; (c) infantile spasms; (d) monotherapy in newly diagnosed epilepsy; (e) adjunctive treatment for partial seizures in children; (f) Rett's syndrome; and (g) startle-induced seizures. Common side effects include headache, dizziness, drowsiness, insomnia, tiredness, nausea, vomiting, diplopia, ataxia, tremor, and allergic rash. Serious side effects include Stevens' Johnson syndrome, toxic epidermal necrolysis, and hypersensitivity syndromes. It may cause severe exacerbation of myoclonic epilepsy. There were occasional reports of exacerbation of other myoclonic seizure disorders.

No significant relationship has been found between lamotrigine plasma levels and its pharmacological effects. A tentative concentration range of 2 to 4 mg/L was originally suggested. A wider range of 3 to 14 mg/L has been noted more recently. Some patients, however, can tolerate lamotrigine concentrations of up to 18 mg/L, whereas side effects develop in others at levels of around 1 mg/L. Routine monitoring of lamotrigine concentrations is, therefore, not recommended. Exceptions may be during pregnancy and when switching patients to lamotrigine from carbamazepine, phenytoin, or sodium valproate.

Drug interaction with other anti-epileptic drugs (AEDs) include (a) sodium valproate, which inhibits the metabolism of lamotrigine and can increase the risk of allergic rash; (b) sodium valproate and lamotrigine, which interact pharmacodynamically to increase the likelihood of tremor; (c) carbamazepine, phenytoin, phenobarbital, which and primidone, which induce the metabolism of lamotrigine; (d) the combination of carbamazepine and lamotrigine, which can result in a pharmacodynamic interaction causing neurotoxic symptoms including headache, nausea, dizziness, and ataxia. Drug interactions with non-AEDs include (a) sertraline, which has been reported to increase lamotrigine concentrations in two patients; and (b) lamotrigine clearance, which has been reported to be accelerated by the analgesic acetominophen. Rifampicin has been reported to induce the metabolism of lamotrigine in healthy volunteers.

Levetiracetam (Keppra) is approved as adjunctive therapy for partial seizures in adults. Clinicians have also used it as monotherapy for of myoclonic seizures in adults, and also use it in children. Common side effects include fatigue, irritability, coordination difficulty, and behavioral abnormalities.

Oxcarbazepine (Trileptal) is FDA approved for monotherapy or adjunctive therapy in the treatment of partial seizures in adults and as adjunctive therapy for partial seizures in children ages 4 to 16. Common side effects include fatigue, nausea, vomiting, abdominal pain, dizziness, and somnolence. A more serious and clinically significant side effect is hyponatremia in 2.5% of patients, and is more commonly found in older patients.

Topiramate (Topamax; TPM) is approved for treatment of partial onset seizures on primary generalized tonic–clonic seizures, in patients aged 2 or older, and in seizures associated with the Lennox–Gastaut syndrome. Clinicians have also used it as monotherapy of myoclonic epilepsy, as a mood stabilizer, and to reduce medication-induced weight gain. Common side effects include fatigue, confusion, expressive speech dysfunction, mood disorders, decreased concentration and attention, paresthesias, and weight loss. More serious side effects include renal stones (1% to 5%) and psychosis (1%).

Drug interactions with other AEDs include (a) TPM levels reduced by phenytoin (48%) and carbamazepine (40%); (b) TPM levels that may elevate phenytoin levels at high phenytoin serum levels; (c) TPM levels that decrease valproate levels 11%; valproate which decreases TPM levels by 14%. Drug interactions with non-AEDs include; (a) TPM reduces extradiol levels by 21% at 400 mg/day (may reduce BCP efficacy); (b) TPM reduces digoxin levels by 12%; (c) TPM may elevate levels of drugs which are metabolized by CYP450 2C19 isozyme.

Other Psychotherapeutic Medications

Fenfluramine, an antiserotonergic anorectic, was initially reported as showing positive effects, but subsequent data from a multicenter study (Campbell, Adams, Perry, Tesch, et al., 1988) and an independent study failed to show any positive effect (Leventhal et al., 1993). Furthermore, this drug was shown to have a retarding effect on discrimination learning in the laboratory (Campbell, Adams, Small, et al., 1988).

Other Medical Treatment Agents

Secretin is a peptide hormone that stimulates pancreatic secretion. After the initial report of positive effect of secretin treatment in three autism subjects (Horvath et al., 1998), many children with autism have received secretin treatment. However, several large sample-controlled studies have failed to demonstrate any significant treatment effect for autism (Chez et al., 2000; Coniglio et al., 2001; Dunn-Geier et al., 2000; Roberts et al., 2001; Sandler et al., 1999). A worsening in autistic symptoms during secretin treatment was noted by Robinson (2001).

Neuropeptide ORG 2766, a synthetic analog of adrenocorticotropic hormone, was studied in 34 autistic children. ORG 2766 was reported to increase the amount and quality of social interaction (Buitelaar et al., 1992a, 1992b). However, in a later study of 50 children with autistic, ages 7 to 15 years, and with a performance IQ of more than 60, ORG 2766 failed to improve social and communicative behavior at group level. Future studies should examine whether ORG 2766 differentially affects various subtypes of autism (Buitelaar, Dekker, van Ree, & van Engeland, 1996).

Niaprazine is a histamine H_1-receptor antagonist with marked sedative properties. Niaprazine was administered at 1 mg/kg/day for 60 days in 25 subjects with autism. A positive effect was noted in 52% of patients, particularly on hyperkinesias, unstable attention, resistance to change and frustration, mild anxiety sign, aggression, and sleep problems (Rossi, Posar, Parmeggiani, Pipitone, & D'Agata, 1999).

R-THBP (6R-L-erythro-5,6,7,8-tetrahydrobiopterin), a cofactor for tyrosine hydroxylase in the biosynthetic pathway of catecholamines and serotonin, was reported as effective in autistic children's social functioning—mainly eye contact and desire to interact, and in the number of words or sounds that the child used (Fernell et al., 1997; Komori et al., 1995).

Vitamins. "Megavitamin" therapy has become a popular form of treatment for a variety of psychiatric disorders. The proponents of orthomolecular psychiatry claim that "mega" doses of certain vitamins will ameliorate or prevent mental disorders such as schizophrenia, mental retardation, and autism. Determining the efficacy of the use of pyridoxine (vitamin B_6) plus magnesium has been controversial. Some short-term (2-week to 30-day) studies reported positive results (Pfeiffer, Norton, Nelson, & Shott, 1995). However, interpretation of these positive findings needs to be tempered because of methodological problems inherent in many of the studies (Pfeiffer et al.). Other investigators, however, could not confirm such findings (Findling, Maxwell, Scotese-Wojtila, et al., 1997; Tolbert, Haigler, Waits, & Dennis, 1993).

Lowe, Cohen, Miller, and Young (1981) gave folic acid and B_{12} to an unselected group of children with autism. No significant change of behavior was noted in these children. Nonetheless, Hagerman et al. (1986) reported behavioral improvement in prepubertal boys with the fragile X syndrome treated with folate 10 mg/day. This finding calls for a trial of folate in autistic children, because about 7.7% of autistic people also have fragile X syndrome (Brown et al., 1986). Gillberg, Whalstrom, Johansson,Tornblom, & Albertson-Wikland (1986) gave folate to four autistic boys with the fragile X syndrome but found no significant behavioral change. Nevertheless, this treatment warrants further exploration.

Diet. The effect of "diet" on individuals with autism has not been systematically studied, though some parents and professionals enthusiastically advocate it. Dietary treatment may be relatively safe; however, it should be undertaken only under the supervision of a knowledgeable dietician or physician to ensure the child's nutritional needs.

N, N-Dimethylglycine (DMG), a dietary supplement, has been reported by nonmedical literature to be beneficial in children with autism. Two recent

published studies failed to find any significant difference between DMG and placebo groups (Bolman & Richmond, 1999; Kern et al., 2001) (Table 12.1).

CLINICAL INDICATIONS FOR PSYCHOPHARMACOTHERAPY IN AUTISM

Accurate interpretation of both signs and symptoms of an illness and side effects of medications by parents and other professionals taking care of individuals with autism is essential for achieving the most effective use of medications. The side effects induced by the psychotherapeutic medications have been described earlier in this chapter. The following section briefly describes the frequently observed or reported "behavioral symptoms or problems" in individuals with autism that actually may be viewed as clinical manifestations of certain diagnosable neuropsychiatric disorders which are potentially medication responsive. In some of the neuropsychiatric disorders, administration of the psychotherapeutic medications has been based on well-documented research. However, the efficacy of medication therapy in other disorders requires further research. Suggestions are made here based on the limited clinical, empirical experience of the present author and of few other investigators as little research has been done in this field.

Co-morbid Psychiatric Disorders

Over the years, investigators in the field of autism have reported that in the autistic population, about 64% had poor attention and concentration; 36% to 48% were hyperactive; 43% to 88% exhibited morbid or unusual preoccupation; 37% presented with obsessive phenomena; 16% to 86% showed compulsions or rituals; 50% to 89% demonstrated stereotyped utterance; 68% to 74% exhibited stereotyped mannerisms; 17% to 74% had anxiety or fears; 9% to 44% showed depressive moods, irritability, agitation, and inappropriate affect; 11% had sleep problems; 24% to 43% had a history of self-injury; and 8% presented with tics (Ando & Yoshimura, 1979, Chung, Luk & Lee, 1990; Fombonne, 1992; Le Couteur et al., 1989; Rumsey, Rapoport, & Sceery, 1985; Rutter & Lockyer, 1967). These investigators, however, did not specifically investigate the incidence of diagnosable psychiatric disorders in their samples because conceptually these additional behavioral and/or psychiatric symptoms have been viewed as "associated features" (Tsai, 1996).

Because of difficulties in communicating with other people, as well as in showing appropriate affect, autistic individuals do not appear to resist their compulsions, to complain about the compulsive acts, or to manifest distress. Hence, they are unable to or are incapable of providing diagnostic

information via structured or semistructured diagnostic interview, or patient self-report scales (Tsai, 1996). This fact raises the possibility that clinicians may hesitate to assign additional psychiatric disorder(s) to persons with autism, particularly in the lower functioning or nonverbal autistic individuals. Nevertheless, there are case reports describing other specific types of psychiatric disorders occurring in autistic individuals. These include reports of unipolar and bipolar affective disorders, OCD, schizophrenia, and Tourette syndrome.

Given the relatively high frequencies of the "associated features" and the increasing case reports of autism associated with other major psychiatric disorders, it is conceivable that a significant number of individuals with autism may also have other coexisting major psychiatric disorders. Thus, to render effective treatment to persons with autism, some modifications of the contemporary diagnostic criteria of certain psychiatric disorders may be required when dealing with the autistic students. For example, the diagnosis of OCD may be considered in lower functioning autistic individuals even in the absence of clear ego-dystonicity (i.e., the child is able to tell whether the obsessive thought is intrusive and beyond his control) that is required by the *DSM-IV* and *ICD-10* for diagnosis of OCD; or the diagnosis of major depression may be considered in nonverbal or lower functioning autistic persons even in the absence of subjectively reported depressed mood, worry, guilty feeling, and suicidal ideation as required by the *DSM-IV* and *ICD-10*. If these "associated" behavioral and psychiatric symptoms can be viewed as symptoms of various co-morbid psychiatric disorders, there are data suggesting that with an appropriate evaluation, premedication workups, a specific diagnosis, and multiple measures of outcome, psychopharmacotherapy can be a safe and efficacious treatment for these symptoms in autistic persons (Tsai, 1996). Thus, to render effective treatment to people with ASD, this chapter does not list the "diagnostic criteria" for various psychiatric disorders, as required by the *DSM-IV* and *ICD-10*. Instead, this chapter describes core features of various neuropsychiatric disorders and symptom clusters as indications for consideration of psychopharmacotherapy.

Resistance to Change, Ritualistic or Compulsive Behaviors, Abnormal Attachments, and Obsessive–Compulsive Disorder

Key features of OCD include obsessions (unwanted ideas, thoughts, images, or impulses that repeatedly well up in the mind of the person with OCD) and compulsions (repetitive behaviors in response to obsessions; most common compulsions are washing and checking). Often the obsessions include persistent fears that harm may come to self or a loved one; an unreasonable belief of having a terrible illness; repeated thoughts about contamination, repeated doubts, religious scrupulousness, an excessive need

for symmetry or exactness, or an excessive need to do things in a particular order or perfectly. Impulses or images may include aggressive or horrific impulses and sexual imagery. These thoughts are intrusive (ego-dystonic), unpleasant, and produce a high degree of anxiety.

Compulsions include counting, repeating words silently, hoarding, and endlessly rearranging objects in an effort to keep them in precise alignment with each other. These behaviors generally are intended to ward off harm to the person with OCD. Some people with OCD have regimented rituals, whereas others have rituals that are complex and changing. Most of the time, people with OCD know that their obsessive thoughts are senseless and that their compulsions are not really necessary, and most people with OCD struggle to banish their unwanted, obsessive thoughts and to prevent themselves from engaging in compulsive behaviors. People with OCD often attempt to hide their disorder rather than seek help, and often they are successful in concealing their obsessive-compulsive symptoms from friends and co-workers. OCD tends to last for years, even decades. The symptoms may become less severe from time to time, but the symptoms are usually chronic. People with OCD struggle against their compulsions; often develop a dysphoric mood; and become irritable, tense, and depressed (APA, 1994).

Many young children with autism have ritualistic or compulsive behaviors that involve rigid routines (e.g., insistence on eating particular foods) or stereotyped, repetitive motor acts, such as hand clapping or finger mannerisms (e.g., twisting, flicking movements carried out near the face). Many autistic children line up toys or objects and become very distressed if these are disturbed. Some children may repetitively flush toilets or turn light switches on and off. There may be a perseverative preoccupation with certain features of objects, such as their texture, taste, smell, color, or shape. Some autistic children may follow extreme food fads. Many autistic children develop intense attachments to odd objects, such as pipe cleaners, small plastic toys, and so forth. The child may carry the object at all times and protest or throw tantrums if the object is removed. Some autistic children develop preoccupations, such as spending a great deal of time memorizing weather information, state capitals, or birthdates of family members. In adolescence, some of these behaviors may develop into obsessional symptoms (e.g., repeatedly asking the same question which must be answered in a specific manner) and compulsive behaviors (e.g., compulsive touching of certain objects). Ritualistic or compulsive behaviors are often displayed more by normally intelligent autistics than by retarded autistics. Some of these obsessive and compulsive symptoms have obvious similarities to those seen in OCD.

It has been observed that about 75% of children with autistic disorder had difficulty in adapting to new situations, were disturbed by changes in the familiar environment, showed a resistance to learning or practicing a

new activity; about 50% to 80% of these children had unusual preoccupations, attachments to unusual objects; rituals or compulsions such as insisting on eating certain particular foods; repeating dialog from radio and television; spending a great deal of time memorizing weather information, state capitals, or birthdates of family members; continually talking about and playing with a single toy; or repetitively writing or drawing numbers, words, maps, and so forth; and about 50% had unusual sensory interests. In high-functioning adults with autistic disorder, about 85% continued to demonstrate stereotyped, compulsive behaviors, including arranging objects.

Due to difficulties in communicating with other people, as well as in showing appropriate affect, autistic individuals do not seem to resist their compulsions, or to complain about the compulsive acts, or to manifest distress. This raises the possibility that clinicians may hesitate to make a superimposed OCD diagnosis in persons with autism. However, it is conceivable that in some higher functioning autistic students, "quasi-obsessive behaviors" may reflect true symptoms of a coexisting OCD. Indeed, several investigators have reported cases with both autistic disorder and OCDs (McDougle, Price, & Goodman, 1990; Rutter, 1985; Tsai, 1992).

Drug of Choice. Clomipramine, or one of the SRIs (citalopram, fluoxetine, fluvoxamine, paroxetine, or sertraline) can be considered in individuals with autism who exhibit "quasi-obsessive and compulsive behaviors" or diagnosable OCD and who do not have seizure disorders. One of the SRIs should be considered in individuals with seizure disorders, if necessary, sequential trials of SRIs. If response is insufficient with a SRI, add buspirone or clonazepam.

In individuals with unusual behaviors such as resistance to change, stereotypies or ritualistic and compulsive behaviors, and unusual attachment that severely interfere with the individual's daily functioning, Haloperidol, clomipramine, or one of the SRIs may be considered (Anderson et al., 1984; Gordon et al., 1993; McDougle et al., 1992, 1996; Mehlinger, Scheftner, & Poznanski, 1990; Tsai, 2001).

Maintenance Medication Therapy for Obsessive–Compulsive Disorder. Clinical evidence indicates that most individuals relapse if SRIs are discontinued. The effective medication should be continued for 6 months. Then taper the dosage gradually until symptoms reemerge. The dosage should be increased to that immediately the symptoms reemerge. These individuals should be treated indefinitely and follow-up by the prescribing physician every 2 to 3 months (Tsai, 2001).

Trichotillomania

Trichotillomania is characterized by impulses to pull out one's hair, often involving multiple sites. Some clinicians have proposed that this condition is a variant of OCD, based on similarities in phenomenology, family history, and response to treatment.

Drug of Choice. Treatment may start with Haloperidol. If response is insufficient, then switch to pimozide or lithium. If response is insufficient with the previously cited medications, the one with best response should be chosen and a SRI or sequential trials of SRIs should be added. Risperidone may be considered when all other conventional medications have failed to show efficacy.

Unusual Responses to Sensory Experiences and Tic Disorders Including Gilles de la Tourette Syndrome

A tic is a sudden, rapid, recurrent, nonrhythmic, stereotyped motor movement or vocalization. The motor tics most commonly involve the head, but could involve the torso and limbs. It is experienced as irresistible but can be suppressed for varying lengths of time. Tics may be exacerbated by stress and attenuated during absorbing activities. Symptoms are greatly reduced during sleep. Tics wax and wane over weeks to months. Common simple motor tics include eye blinking, neck jerking, shoulder shrugging, and facial grimacing. Common simple vocal tics include throat clearing, grunting, sniffing, snorting, coughing, and barking. Common complex motor tics include facial gestures, grooming behaviors, jumping, touching, stamping, and smelling an object. Common complex vocal tics include repeating words or phrases out of context, corpolalia (use of socially unacceptable words, frequently obscene, in about 30% of cases), palilalia (repeating one's own sounds or words), and echolalia. Rare complications of severe tic disorders include self-injurious behaviors (head banging, striking oneself, picking skin) and orthopedic problems (from knee bending, neck jerking, or head turning). The tic disorders can be subclassified based on duration and variety of tics. Transient tic disorder includes motor and vocal tics lasting for at least 4 weeks but for no longer than 12 consecutive months. Tourette disorder and chronic motor or vocal disorder can have a duration of more than 12 months but are distinguished by the requirement for Tourette disorder that there be multiple motor tics and at least one vocal tic (APA, 1994).

Many autistic persons display tic-like symptoms such as grimacing; hand flapping or twisting; toe walking, lunging, jumping, darting, or pacing; body rocking and swaying; and head rolling or banging. In some cases they may appear intermittently, whereas in other cases they are continuously present. They are usually interrupted by episodes of immobility and odd posturing

with head bowed and arms flexed at the elbow. Some of these symptoms have obvious similarities to those seen in tic disorders.

It has been reported that about 70% of people with autistic disorder had stereotyped hand–finger mannerisms and stereotyped utterances; 25% to 40% had self-injury; about 10% had tics. There are some recent studies describing the development of Tourette disorder in autistic individuals (Barabas & Matthews, 1983; Comings & Comings, 1991; Realmuto & Main, 1982; Sverd, Montero, & Gurevich, 1993). I have also seen a few such cases. It is unclear, however, how frequently the two disorders might occur coincidentally. It is also uncertain how this finding might be linked to the etiology of the two disorders. This remains one of many areas requiring further investigation.

Drug of Choice. In patients with the previously described tic-like symptoms or with a clear diagnosis of Tourette disorder, Haloperidol or pimozide should be tried first because each is more potent than clonidine. In some cases, the combination of Haloperidol or pimozide with a SRI may be needed in some severe cases. Risperidone or calcium channel blockers such as verapamil (Calan) or nifedipine (Adalat) may be considered when all other conventional medications have failed to show efficacy (Tsai, 2001).

Disturbance of Motility and Attention Deficit Hyperactivity Disorder

Many young children with autism are markedly overactive. The literature has reported that about 50% of children with autistic disorder were hyperactive, impulsive, and had poor attention and concentration. It is conceivable that a significant number of children with ASD may also have coexisting ADHD.

Two core symptom clusters characterize the essential feature of ADHD: inattention and hyperactivity and impulsivity in two or more settings, for example, home, school, and physician's office. The classic presentation involving both symptom clusters is called ADHD, combined type; individuals with prominent symptoms from only one cluster may be diagnosed with ADHD, predominately inattentive type or ADHD predominately hyperactive type. The symptoms of inattention include failure to give close attention to details; making careless mistakes in schoolwork, homework, or other activities; difficulty in sustaining attention in tasks or play activities; failure to listen when spoken to directly; not following through on instruction and failure to finish schoolwork, chores, or duties in the workplace; difficulty in organizing tasks and activities; avoiding or being reluctant to engage in tasks requiring sustained mental effort; losing things necessary for tasks or activities; being easily distracted by extraneous stimuli and forgetful in daily

activities. The symptoms of hyperactivity include excessively fidgeting with hands or feet or squirming in seat; leaving seat in classroom or in other situations in which remaining seated is expected; running about or climbing excessively; difficulty in playing or engaging in leisure activities quietly; on the go as if driven by a motor; and excessive talking. The symptoms of impulsivity include blurting out answers before questions have been completed; difficulty in waiting for a turn in games; and often interrupting or intruding on others. The ADHD problems persist into adolescence and adulthood in approximately 30% to 70% of the individuals (APA, 1994).

Drug of Choice. In low- or middle-functioning individuals with autism or in individuals with higher functioning autism with other neurological disorders such as seizure disorders and Tourette disorder, sequential monotherapy trials may be considered with atomoxetine (Strattera), clonidine, and guanfacine, for hyperactivity and impulsiveness; or sequential monotherapy trials may be considered with TCAs (imipramine, desipramine [Norpramin], nortriotyline [Pamelor]), bupropion (Wellbutrin), and naltrexon (ReVia), for inattention, impulsiveness, and hyperactivity. In high-functioning individuals without other neurological disorders, stimulants such as methylphenidate or amphetamine(s) may be tried first. Atomoxetine, guanfacine, clonidine, and imipramine may be considered in patients who do not respond to stimulants or in high-functioning individuals who have other neurological disorders (Tsai, 2001).

Unusual Nervousness, Overanxious Behaviors, Generalized Anxiety Disorder and Panic Attack, and Phobic Disorders

It has been reported that among individuals with autistic disorder, about 20% to 60% had fears or phobia, and about 75% had separation anxieties. It is conceivable that some of these individuals might indeed have general anxiety disorder (GAD) or panic attack. However, due to clinicians' lack of experience working with this particular population, the possibility of coexisting GAD and panic attack has never been considered in these subjects or in other autistic individuals with similar clinical features.

The essential features of GAD are persistent anxiety and worry associated with some of the following symptoms occurring more often than not for at least 6 months or longer: (a) motor tension: shakiness, jitteriness, jumpiness, trembling, tension, muscle aches, fatigue, inability to relax, eyelid twitch, furrowed brow, strained face, fidgeting, restlessness, easily startled; (b) autonomic hyperactivity: sweating; heart pounding or racing; rapid or irregular heartbeat; cold, clammy hands; dry mouth; dizziness; lightheadedness; paresthesias (tingling in hands or feet); upset stomach; hot or cold spells; frequent urination; diarrhea; nausea; discomfort in the pit of the

stomach; lump in the throat; flushing; pallor; high resting pulse; high respiration rate or breathing problem; (c) apprehensive expectation: anxiety, uneasiness, feeling of apprehension, worry, fear, rumination, and anticipation of misfortune to self or others; (d) vigilance and scanning: hyperattentiveness resulting in distractibility, difficulty in concentrating or mind going blank, insomnia, feeling "on edge," irritability, impatience.

Panic disorder is characterized by recurrent unexpected panic attacks with a discrete period of intense fear, terror, heightened arousal, or anticipatory anxiety that is accompanied by some of the following somatic or cognitive symptoms without apparent cause: palpitations, pounding heart, or accelerated heart rate; sweating; flashing; trembling or shaking; sensation of shortness of breath or smothering (dyspnea); feeling of choking; chest pain or discomfort; nausea or abdominal distress (butterflies in the stomach); feeling dizzy, unsteady, lightheaded, or faint; derealization (feeling of unreality) or depersonalization (being detached from oneself); fear of losing control, or despair, or going crazy; sense of catastrophic fear of dying; paresthesia (numbness or tingling sensations); and chills or hot flashes. Most individuals will have many of the symptoms during an attack, but not necessarily every possible symptom. There is also a group who have these attacks without the subjective sense of anxiety or who experience insufficient symptoms to meet diagnostic criteria (i.e., limited symptom attacks). Individuals may develop three distinct disorders: (a) the panic attack itself, (b) a secondary anticipatory anxiety making them feel that they will have another episode in certain places, and (c) a phobic avoidance of the feared situation. These symptoms typically occur in public places, such as supermarkets, restaurants, elevators, and crowded stores (APA, 1994).

All phobic disorders are characterized by disabling anxiety (at times also associated with panic attacks) and avoidance because of exposure to places or situations from which one cannot escape (agoraphobia), specific feared objects or situations (e.g., heights, snakes, thunderstorm; specific phobia), and certain types of social or performance situations (e.g., of being unable to answer questions in social situations and of choking when eating in front of others; social phobia).

Panic reactions, phobias, and performance anxiety may all lead quickly to discharge in the form of self-injurious or aggressive outbursts, or stereotypic motor behaviors. The discharge behavior tends to be reinforced by removing the provoking agent, and the avoidant behavior tends to generalize to a wider arena. This may result in a pattern of phobic avoidance with recurrent panic attacks.

Drug of Choice. The preferred medication for anxiety disorders is buspirone (BuSpar) or SRIs such as fluoxetine, fluvoxamine, paroxetine, sertraline. The benzodiazepines such as alprazolam (Xanax), diazepam (Valium),

chlordiazepoxide (Librium or Librax), and lorazepam (Ativan) are the second line of drugs of choice because there is a potential for development of tolerance and dependence as well as the possibility of abuse and withdrawal reactions. When the benzodiazepines are prescribed, they should be used for just brief periods of time. For treatment of acute anxiety, the medication chosen should be at the lowest possible dosage for the shortest possible time. Dosages should be flexible rather than arbitrary and should be taken intermittently at a time of increased symptoms rather than on a fixed daily schedule. In general, 1 to 7 days of medication treatment is recommended for a reaction to an acute situational stress, although 1 to 6 weeks of treatment may be needed for short-term anxiety due to specific life events. Clinical judgment plays a major role in the decision to continue anxiolytic treatment beyond 4 to 6 weeks. Although long-term administration may maintain initial improvement, it is unlikely to result in further gains. The chronic nature of anxiety disorders and the frequency of eventual relapse after treatment discontinuation, however, suggest that in some individuals, long-term treatment may be indicated. Periodic reassessment of the efficacy, safety, and necessity of long-term anxiolytic therapy is necessary because the high rate of co-morbidity for GAD with other psychiatric disorders suggests that an alternative approach (such as adding an antidepressant while tapering of an anxiolytic medication) may be more appropriate in certain individuals.

For treatment of panic attacks, agoraphobia, and social phobia, a SRI should be considered first. If response is insufficient, then add alprazolam or clonazepam.

For treatment of specific phobia, propranolol should be tried first. If response is insufficient, add a MAOI (e.g., Phenezine).

Disturbance in Mood and Affect—Major Depressive Episode, Hypomanic and Manic Episodes and Bipolar Mood Disorder

Major Depression. All forms of depressive mood and affective disorder occur in persons with autism who are less likely to seek or be referred for help for subjective dysphoria. In the absence of problematic behavior, depression and social withdrawal are often ignored by caregivers. For those affectively disordered who have disruptive symptoms, there is a tendency to focus on the problem behaviors without sufficient attention to the underlying affective disturbance.

Major depression may occur during adolescence and adult life. Major depressive disorder can also occur in children as young as 6 years of age. The depression may be a reaction to partial realization of handicaps. This is more likely seen in those of higher level of ability. However, depression can also be seen in lower functioning individuals. Chung et al. (1990) reported

that 9% of the 66 autistic children in Hong Kong had depressive mood; 44% had irritability or agitation; 29% showed inappropriate affect; and 11% had sleep problems. Investigators had reported cases with both autistic disorder and unipolar and bipolar affective disorders (Gillberg, 1985; Komoto et al., 1984; Lainhart & Folstein, 1994; Steingard & Biederman, 1987), and schizophrenia (Clarke et al., 1989; Petty et al., 1984; Volkmar & Cohen, 1991).

The essential features of depressive disorders include the following symptoms: depressed mood as indicated by either subjective report or observation made by others (in children and adolescents it can be irritable mood, sad expression, sad tone of voice, and fearfulness); diminished interest or pleasure in all, or almost all activities including a change in response to behavioral "rewards"; significant weight loss when not dieting or weight gain or decrease or increase in appetite; insomnia or hypersomnia; psychomotor agitation or retardation; fatigue or loss of energy; somatic complaints such as headache or gastrointestinal distress; feeling of worthlessness or inappropriate guilt; diminished ability to think or concentrate; indecisiveness, becoming unable to perform usual activities of daily living or prevocational tasks; deterioration in self-care and regression in function (poor hygiene); increased self-injurious behaviors and repetitive stereotypies; recurrent thoughts of death; recurrent suicidal ideation without a specific plan; or a suicide attempt or a specific plan of committing suicide; psychotic features, including mood-congruent or incongruent delusions; and hallucinations (APA, 1994).

Hypomania or Mania. It is very rare that young children with autism develop hypomania or mania. However, their hyperactivity, impulsivity, mood swings with irritability and periodic laughing, and grandiose talks sometimes may be diagnosed as symptoms of hypomanic or manic episodes by clinicians who are not familiar with autism. On the other hand, because of bipolar mood disorders in family members, some persons with autism may develop hypomania or mania when they are treated with antidepressants such as TCAs or SRIs; or they may develop hypomanic or manic episodes in adolescence or adulthood. Therefore, it is important to learn about the features of hypomania, mania, and other mood disorders.

The essential features of mania include a distinct period of an elevated, expansive, or irritable mood; inflated self-esteem ranging from uncritical self-confidence to marked grandiosity, often reaching delusional proportions; decreased need for sleep; hyperactivity; hypersexuality; more talkative than usual or pressure to keep talking at times so pronounced that it becomes incomprehensible; flight of ideas or subjective experience that thoughts are racing; distractibility; a significant increase in pleasurable but risk-taking activities (e.g., overspending) that have a high potential for painful consequences; lability of affect characterized by rapid shifts from euphoria to

anger; increased psychomotor agitation, irritability, aggressiveness, or self-injurious behavior when the goal-directed behavior is thwarted; and florid psychotic features (e. g., delusions and hallucinations) (APA, 1994).

Hypomania is a less severe form of its manic counterpart, typically without many of the consequences experienced during an acute, full-blown episode. Subtle indicators of hypomania may include a transition period in and out of depression; increased productivity; heightened perceptions; symptom overlap and fluctuation; and an altered view of spouse, friends, and others (APA, 1994).

Bipolar Mood Disorders

Bipolar I disorder is characterized by a history of one or more manic episodes and one or more mixed or major depressive episodes. This category can be further subclassified as either manic, hypomanic, mixed, or depressed in presentation. Bipolar II disorder is defined by the presence or history of at least one hypomanic episode and at least one major depressive episode, but never presenting with a full manic or mixed episode (APA).

Treatment Phases of Major Depressive Episode

Major depressive disorder is frequently a recurrent illness; thus, treatment is divided into three phases: (a) acute therapy to induce a remission, (b) maintenance therapy to prevent a relapse into the current episode, and (c) prophylactic therapy to prevent recurrence after at least 6 months of full remission from a prior episode.

Drug of Choice for an Acute Depressive Episode. The drug of choice should be started with one of the following: a SRI, Venlafaxine, or Nefazodone; and if necessary, with a sequential trial of SRIs. If response is partial, the dose should be combined with a lithium or thyroid supplement, or with Pindolol. If the response is insufficient, a second antidepressant should be added (e.g., add a TCA slowly to a SRI). If the response is still insufficient, ECT should be added. If psychosis emerges, an antipsychotic neuroleptic should be added.

Drug of Choice for Major Depressive Episode With Marked Anxiety, Panic Attacks, or Agitation. Benzodiazepines or trazodone plus an antidepressant should be administered (not with Nefazodone). If the response is insufficient, a sequential trial of SRIs should be added. If response is still insufficient, the class of antidepressant should be switched (e.g., from SRI to bupropion). If response is still insufficient, an antidepressant of a different class should be added (e.g., a SRI plus bupropion). If response is insufficient, a mood stabilizer should be added (e.g., valproic Acid). If response is still

insufficient, an ECT should be added. If psychosis emerges, an antipsychotic neuroleptic should be added.

Drug of Choice for Depressive Episode of Bipolar Mood Disorder. This should begin with an antidepressant plus a mood stabilizer. If response is partial, dosage should be combined with lithium or thyroid supplement or Pindolol. If the response is still insufficient, two different antidepressants should be used concurrently. If response is still insufficient, an ECT should be added. If psychosis emerges, an antipsychotic neuroleptic should be added.

Maintenance and Prophylactic Therapy of Depressive Episodes

Maintenance therapy refers to prevention of a relapse back into the current episode. Maintenance therapy is mandatory following successful induction of a remission. It should be continued for 6 to 12 months after an acute depressive episode. After 12 months, medications can usually be tapered over a period of several weeks to avoid autonomic rebound or SSRI discontinuation syndrome. If symptoms reemerge, medication should be reinstated and maintained for an additional 3 to 6 months before an attempt is made to taper them again.

Prophylaxis refers to the prevention of recurrent episodes. Prophylaxis involves the indefinite continuation of medication, usually over many years; if the episodes have short prodromes or develop insidiously, continuous prophylactic therapy would be more appropriate. In individuals with recurrent severe unipolar depressions and high risk of suicide, indefinite prophylactic treatment with an antidepressant with least adverse effects may be required.

Medication Treatment of Acute Manic Episode

Drug of Choice for the Treatment of a Manic Episode. With mild to moderate symptoms, lithium or divalproex sodium should be given. If response is insufficient and with marked agitation, a benzodiazepine should be added. If the response is still insufficient, an antipsychotic neuroleptic should be added. If response is still insufficient and patient seems in immediate danger, an ECT should be added after lithium is discontinued.

Maintenance and Prophylaxis Therapies for Manic Episodes. The majority of bipolar individuals who have a manic or depressed episode will have one or more recurrences. Therefore, it is critically important to develop effective and safe long-term treatments. Lithium or divalproex sodium responders, after remission of first acute episode or recurrent episode, should be on the medication for 1 to 2 years and followed up by the prescribing physician every 2 to 3 months. The medication should be slowly tapered over several weeks. If relapse occurs, blood level should be checked or the medication

should be resumed for an indefinite length of time during therapy, followed up by the prescribing physician every 2 to 3 months. Thyroid supplementation should be added if TSH is elevated.

Self-Injurious Behaviors

Self-injurious behavior (SIB), such as head banging, finger biting, handbiting, or wrist biting; or scratching of face or extremities, may occur in lower functioning individuals with autism. SIB may be constant (compulsive SIB) or intermittent (paroxysmal SIB) or occasional (episodic SIBs). Some SIBs may relate to other neuropsychiatric disorder such as Tourette disorder. Other SIBs may relate to frustrations of the autistic individuals. However, caregivers usually have difficulties with figuring out the reasons of the SIBs in their children or clients due to the autistic persons' communicative difficulties. SIB is a behavior that affects the persons with autism as much as it does their caregivers. The only established treatment with some effectiveness has been various behavioral interventions which require an extraordinary investment in time and professional effort. However, there are only a few intensive and effective treatment programs in the United States. Hence, only a minority of people with severe SIB have received intensive behavior treatment. For most autistic individuals with severe SIB, physical restraint with helmets, handcuffs, or leather straps is the usual treatment.

Drug of Choice. Effective pharmacotherapy for SIB has not been established. At present, if self-injurious behaviors develop as a part of Tourette disorder, the medications for Tourette disorder should be considered first. Sequential trials of naltrexone or trazodone or fluoxetine may be considered in individuals who do not respond to the previously cited medications or in individuals whose SIBs do not have readily identifiable causes. These trials should be considered as well if intensive behavioral treatment is not available to these individuals (Tsai, 2001).

Aggressive Behaviors

Some individuals with autism may become agitated and physically attack other people, or destroy objects or properties. Some of the aggressive and destructive behaviors may relate to frustrations of these individuals due to their inability to cope with task demands, difficult and challenging games and toys, or dysfunctional and broken toys; or due to their being stopped from doing things and activities they like; or due to caregivers' attempts of using physical of these individuals. Some aggressive and destructive behaviors are precipitated by drastic mood change due to a restraining mood disorder. There are, however, some aggressive and destructive behaviors that do not seem to have any clear causes but are mostly being driven by powerful

and unanticipated emotions such as anger or fear. Nevertheless, aggressive behaviors are of great concern because of their devastating effect.

Impulsive disorder and mood disorder-related aggressive and destructive behaviors may respond to some medications. Aggressive behaviors without clear reason(s) tend not to respond to drugs, except to the extent that they produce sleep and apathy in these individuals.

Drug of Choice for Aggressive and Destructive Behaviors Due to Inabilities to Cope With Task Demands, Difficult and Challenging Games and Toys, or Dysfunctional and Broken Toys. Clonidine or Atomoxetine should be administered. If response is insufficient, patient should be switched to a SRI (as low a dose as possible).

Drug of Choice for Aggressive and Destructive Behaviors Due to Being Stopped From Doing Things and Activities He or She Likes. A low dosage of a SRI should be administered. If response is insufficient, sequential trials of other SRIs should be added. If response is still insufficient, a small dosage of Risperdal should be added.

Drug of Choice for Aggressive and Destructive Behaviors Due to Mood Disorder. Lithium or divalproex sodium should be administered. If response is insufficient, benzodiazepines should be added. If the response is insufficient, an antipsychotic neuroleptic should be added. If response is still insufficient and patient is in immediate danger, ECT after lithium should be discontinued.

Drug of Choice for Aggressive and Destructive Behaviors for No Apparent Reasons. Clonidine should be administered. If response is insufficient, the Clonidine should be discontinued, and a SRI should be added, and if response is insufficient, sequential trials of other SRIs should be considered. If response is still insufficient, the SRI should be discontinued, and sequential trials of an antipsychotic neuroleptic, trazodone, divalproex sodium, propranolol, a benzodiazepine, or lithium should be considered (Tsai, 2001).

Unusual Sleeping Patterns

At some stage during childhood, particularly under 8 years of age, the majority of autistic children were reported as having sleep problems including one or more of extreme sleep latencies (difficulty falling sleep), lengthy periods of night waking and shortened night sleep; early waking, and excessive daytime sleepiness (Elia et al., 2000; Patzold, Richdale, & Tonge, 1998; Richdale & Prior, 1995; Taira, Takase, & Sasaki, 1998; Takase, Taira, & Sasaki, 1998; Tsai, Chu, & Biederman, 1997). These individuals tended

to keep the whole family awake every night because of their unusual sleep patterns. Other investigators, however, questioned parental oversensitivity to sleep disturbance of their autistic children (Hering, Epstein, Elroy, Iancu, & Zelnik, 1999; Schreck & Mulick, 2000).

There are several different types of sleep disturbances (disorders). *Primary sleep disorders* can be divided into three major groups:

1. *Dyssomnias.* Primary insomnia is characterized by difficulty initiating or maintaining sleep or by not feeling rested after an apparently adequate amount of sleep for at least 1 month. Further, it causes significant stress or impairment in various areas of functioning. This condition may represent a lifelong pattern of poor sleep habits or it may develop as a result of distressing events but then persists after the stressor resolves. It is characterized by excessive daytime worry about being able to fall or stay asleep.

2. Hypersomnia is characterized by excessive daytime sleepiness for at least 1 month. The daytime sleepiness (falling asleep easily and unintentionally) is not accounted for by an inadequate amount of nighttime sleep. Another criterion is the presence of hypersomnia nearly every day for at least 1 month or episodically for longer periods of time, resulting in occupational or social impairment.

3. *Parasomnia. Nightmare disorder,* formerly known as dream anxiety disorder, is a condition that involves vivid dreams, often characterized by recurring themes of threats to survival, security, or self-esteem. Because the dreams are most likely to occur during rapid eye movement (REM) sleep, autonomic agitation is minimal during the dream but may occur upon awakening. The diagnosis is not made if the dreams are attributable to a known organic factor, such as a medication or general medical condition. *Sleep terror disorder,* also known as pavor nocturnes, is characterized by recurrent episodes of abrupt awakening from sleep in the first third of the major sleep episode, usually during non-rapid-eye-movement (NREM) periods. The episode can be dramatic and is likely to begin with a panicky scream. The person often sits up in bed, exhibiting signs of intense anxiety and autonomic arousal (e.g., tachycardia, rapid breathing and pulse, dilated pupils, sweating, etc.), and may be confused, disoriented, and unresponsive to comforting gestures. Individuals may describe a sense of terror and fragmentary images but are usually unable to recount a complete dream. *Sleepwalking disorder* (*somnambulism*) is characterized by episodes of complex behaviors that initially include sitting up and performing perseverative movements (e.g., picking at the sheet). It usually occurs during NREM sleep. Sleepwalking disorder often proceeds to such activities as leaving the bed, walking, dressing, and opening or closing windows and doors.

Secondary sleep disorders are related to other medical or mental disorders and also can characterized by insomnia, hypersomnia, or parasomnia.

One particular secondary sleep disorder that may tend to be overlooked by the caregivers, including physicians, is breathing-related sleep disorder. Breathing-related sleep disorder is a potentially life-threatening abnormal respiratory condition. It includes cessation of both nasal and oral air flow (apnea), which in some individuals may last up to 2 minutes. The most prominent sign is loud snoring. Typical complications include insomnia and excessive daytime sleepiness due to frequent nighttime awakenings. There are three forms of breathing-related sleep disorders: (a) obstructive sleep apnea involving blockage of the oropharynx, (b) central sleep apnea involving lack of diaphragmatic effort, (c) central alveolar hypoventilation, which most commonly occurs in very overweight individuals.

Drug of Choice for Treatment of Primary Insomnia Due to Poor Sleep Habit. Sleep hygiene techniques should be initiated, including sleep restriction (e.g., minimum to no afternoon or evening nap and appropriate bedtime), stimulation control (e.g., no stimulating activities including TV watching in evening, lighting and sound control of the bedroom, and limited fluid intake in evening), and relaxation techniques (e.g., appropriate reading or music and bedtime muscle-relaxation exercises). If response is insufficient, add a small dose of clonidine or melatonin for initial insomnia (not setting); or melatonin, trazodone, short- to intermediate-acting benzodiazepin (e.g., ProSom) (sequential trials if necessary) for waking up after 2 to 3 hours of sleep or waking up early in the morning. If a benzodiazepine is used it should be prescribed at the lowest possible dose for the shortest possible time, and on an intermittent rather than on a regular basis. If effective, the medication should be discontinued after 1 to 2 months and the need for a sleep medication should be reevaluated. If response is still insufficient, patient should be switched to a sedative–hypnotics (e.g., Zolpidem [Abien]; for no more than 3 weeks).

Drug of Choice for Treatment of Sleep Disorder Due to Other Mental Disorders or a General Medical Disorder. The mental disorder or general medical disorder should be treated. If response is insufficient, the previously cited treatment recommendations should be implemented.

Drug of Choice for Treatment of Sleep Disorder Due to Prescribing Medication. The patient should be switched to a different medication with equal effectiveness but one without side effect of insomnia. If response is insufficient, the previously cited treatment recommendations should be used.

Drug of Choice for Treatment of Sleep Terror Disorder and Sleep Walking Disorder. These two disorders are much more distressing to parent than to child, and unpredictable and infrequent in occurrence (usually not more

than once a week), which hardly justifies keeping a child under constant medication with its consequent risks. Furthermore, there is strong indication that children will outgrow these disorders. However, if after a thorough assessment and determination that medication treatment is appropriate (e.g., sleep walking becomes potentially dangerous), a benzodiazepine such as Valium or a TCA such as Elavil should be administere. The benzodiazepine should be prescribed at the lowest possible dosage for the shortest possible time, and on an intermittent rather than on a regular basis. The need of continuation of the benzodiazepine or TCA should be reevaluated after 1 to 2 months of good response.

Drug of Choice for Treatment of Breathing-Related Sleep Disorder. Treatment of sleep apnea may include medical measures such as weight reduction and administration during sleep of air under continuous pressure through the nasopharynx. Acetazolamide (Diamox, an AED) may be helpful.

Problem With Enuresis

Some children with ASD may have difficulty with toilet training. They may continue to have problems with unintentional urination (Enuresis) beyond the usual age of toilet training, usually 6 years for boys and 5 years for girls. About 10% of 6-year-olds suffer from nocturnal enuresis (bed wetting) according to studies in the United States, UK, Israel, and African. There is a spontaneous remission rate of 15% per year thereafter. Nocturnal enuresis does not have an identifiable organic etiology in 97% to 99% of the cases (primary enuresis). The organic causes of nocturnal enuresis are diabetes mellitus, diabetes insipidus, sleep apnea, urinary tract infection, neurogenic bladder, and so forth. Among the most commonly accepted etiological factors associated with nocturnal enuresis are smaller than normal bladder capacity, bladder-sphincter dysfunction, nocturnal pylori due to a relative vasopressin (ADH) deficiency, and impaired arousal from deep or delta sleep.

Drug of Choice for Treatment of Nocturnal Enuresis. Nonmedical treatment should be initiated. If medication treatment is decided on, DDAVP or Ditropan should be used in children under 7 years of age; and DDAVP, Ditropan, Detrol, and Tofranil (if necessary, sequential trials) should be used in children older than 7 years. When Tofranil is used, it should be tapered after 3 to 6 months; Ditropan should be tapered after 2 months; and DDAVP should be tapered after 2 months to evaluate the further need for medication.

Problems With Social Withdrawal

Although both low-IQ and high-IQ autistic children are similar in terms of the main symptoms associated with autism, those with a lower IQ show a more severely impaired social development and are more likely to be socially withdrawn. Some individuals with autism become socially withdrawn because of lack of interest in other people or social activities; others' social withdrawal may be due to years of negative and unpleasant experiences.

Drug of Choice. In individuals who are not interested in social activities, naltrexone and fluoxetine may be considered. In individuals whose social withdrawal is related to depressive disorder, a SRI should be added (as low a dosage as possible). If response is insufficient, sequential trials with other SRIs or BuSpar should be added.

Eating Problems

It is not infrequent that individuals with autism have problems with eating. The majority have problems with "picky eating"; others are "hungry all the time." The reasons for these eating problems are not always clear. In some individuals, sensitivity or being obsessive–compulsive to the taste, smell, color, or texture of foods or drinks may be the reason for picky eating. In other individuals, boredom, depressive disorder, anxiety, or side effects of prescribing medications may be the cause for being hungry all the time. The role of medication treatment in these individuals has yet to be defined. Overall, individuals with ASD tend not to develop other eating disorders such as anorexia nervosa or bulimia nervosa, though there were case reports in some of the literature.

Drug of Choice. In individuals with picky eating, sequential trials with SRIs may be considered. If the response is insufficient, an atypical neuroleptic such as olanzapine, risperidone, or quetiapine may be added, which tends to increase the appetite. The atypical neuroleptic, however, should be used on a short-term basis. In individuals who are hungry all the time due to boredom, if use of a medication is considered, a trial of a stimulant may be considered. In individuals whose hungry all the time is due to taking a prescribed medication, the individual should be switched to a medication that causes less severe side effects of increased appetite. If the response is insufficient, sequential trials with stimulants should be added.

Schizophrenia and Other Psychotic Disorders

Most individuals with autism do manifest symptoms of social isolation, impairment in role functioning or grooming, and inappropriate affect.

Many higher functioning people with autism exhibit illogical thinking, incoherence, and poverty in content of speech. Their lack of nonverbal communication may be seen as exhibiting blunt affect. Some individuals with autism have inappropriate laughing or weeping episodes due to an inability to comprehend the meaning of events. Such behavior may be interpreted as labile or abnormal affect. Some higher functioning verbal persons with autism have unusual beliefs (e.g., strongly believe that there is no air in other states), idiosyncratic interests (e.g., a 6-years-old spending an enormous amount of time studying insects), or abnormal sensory experiences (e.g., seeing other people's faces in the air when alone in the room) bordering on delusions or hallucinations. These symptoms have frequently been interpreted by clinicians unfamiliar with autism as clinical manifestations of schizophrenia and other psychotic disorders. Hence, some individuals with autism may be misdiagnosed as having schizophrenia or other psychotic disorder. However, one well-established finding is that children with autism almost never develop a thought disorder with delusions and hallucinations. Only a few well-diagnosed autistic children have been reported to have developed schizophrenia during follow-up periods (Petty, Ornitz, Michelman, & Zimmerman, 1984). Nonetheless, it is important to have some knowledge of what is schizophrenia.

Schizophrenia is characterized by a history of deterioration from a higher level of function and symptoms of hallucinations; and cognitive disturbances such as illogical or tangential thinking, paranoia, delusions, bizarre rituals and behavior, withdrawal, and blunting of affect. Examples of delusions and hallucinations include audible thoughts (i.e., voices speak the patient's thoughts out loud); voices arguing (e.g., two or more voices argue or discuss issues, sometimes referring to the patient in the third person); voices commenting on the patient's behavior; somatic passivity believed to be imposed by outside forces; thought withdrawal by outside forces, leaving the patient feeling as if his or her mind is empty; thought insertions by outside forces; thought broadcasting (i.e., thoughts escape from the patient's mind and are overheard by others); impulsive volitional acts, or feelings that are not one's own but are imposed by outside forces; delusional perceptions (i.e., the individual attributes delusional meaning to normal perceptions; APA, 1994).

Drug of Choice. The introduction of newer atypical or novel neuroleptics such as Clozaril, Risperdal, Zyprexa, Seroquel, Geodon, and Abilif has dramatically affected the decision-making process in choosing an antipsychotic medication. These new agents both minimize neurological adverse effects and qualitatively improve at least some psychotic symptoms (i.e., negative, cognitive, and mood) to a greater degree. There is, however, no evidence that combining two neuroleptics is superior to bioequivalent amounts of a single agent. One exception may be the combined use of a traditional

neuroleptic with an atypical neuroleptic (e.g., Haldol plus Zyprexa) or, alternatively, the combination of two different atypical neuroleptics (e.g., Clozaril plus Risperdal) because these atypical neuroleptics may be sufficiently different that, when combined with each other or with a traditional neuroleptic, a better overall effect can be achieved in selected patients.

Because the onset of improvement is approximately 1 to 2 weeks with most antipsychotic medications, one should start with a low to moderate dose that is maintained for that period. Although dosage can be adjusted more frequently to control adverse effects, it should not be adjusted daily on the basis of therapeutic effect because of the length of these agents' half-lives.

Seizure Disorders

Individuals with autism are particularly vulnerable to the development of seizure disorders (also called epilepsy). During the first decade of life, the incidence of epilepsy in children with autism is higher than that in the general population. Epilepsy has been noted in 4% to 42% of autistic persons (Giovanardi, Rossi, Posar, & Parmeggiani, 2000). Several reports have suggested that many autistic individuals first develop seizures in adolescence (Deykin & MacMahon, 1979; Rutter, 1984). Volkmar and Nelson (1990) reported that risk for developing seizures in the autistic subjects is highest during early childhood. A prospective study of epilepsy in children with ASD found that about 5% of those with an autistic condition had epilepsy. Most had onset of seizures before age 1 year (Wong, 1993). In a retrospective study of 60 patients (mean age 17 years and 2 months), the prevalence of EEG paroxysmal abnormalities without epilepsy was 6.7%; seizure onset was after age 12 years in 66.7% of cases; and the most common type of epilepsy was partial in 45% (Rossi, et al., 1995) to 65.2% (Giovanardi, et al.). Rossi Parmeggiani, Bach, Santucci, and Visconti (1995) noted that EEG paroxysmal abnormalities were mostly focal and multifocal. Females with autism seemed to be more frequently affected by seizures than were males (Elia, Musumeci, Ferri, & Bergonzi, 1995). Individuals with autism and with both a severe mental deficit and a motor handicap are at greatest risk for seizure disorder.

In the North Carolina Autism Society survey study (Aman, Van Bourgondien, Wolford, & Sarphare, 1995), among individuals with autism, the numbers given for different seizure frequencies were as follows: (a) more than one seizure per month, about 19%; (b) more than three seizures per year but less than one a month, about 12.0%; (c) less than three per year, about 15%; (d) none in the last year, about 9%; (e) none in the last 2 years, about 5%; (f) none in the last 3 years, about 32%; (g) no seizures observed, about 8%.

Although the most common type of seizure is the generalized tonic–clonic seizure, other types of seizure disorders have been observed in individuals with autism. Because the various features of different types of seizure disorders may be difficult to be differentiated with features of autism or other neuropsychiatric disorders, it is critical that caregivers learn about clinical features and managements of various seizure disorders. This is the only way to ensure early differentiation and identification of seizures as well as to enhance effective treatments in these individuals.

Depending on the kind of seizures an individual has, and how successful treatment is in preventing them, epilepsy can be anything from a relatively mild, self-limiting disorder with few long-lasting effects, to a persistent, devastating condition that affects almost everything the individual does. The following sections briefly describe the clinical manifestations of the more frequently observed seizure disorders and the general medical treatments in individuals with seizure disorders. These sections are not meant to be a comprehensive guide for assessment, diagnosis, and treatment of seizure disorders, which certainly should be left to specialists in the area (i.e., neurologists specialized in seizure disorders). Rather, they are meant to inform caregivers to recognize an epileptic seizure when it happens and work with the child's doctor when antiseizure drugs (AEDs) are used to control the epilepsy.

Subtypes of Seizure Disorders. Individual seizures are characterized as either focal or partial or generalized, depending on the initial abnormality seen on EEG recordings of the seizure event. Partial seizures arise from a particular brain region, often identifiable on cerebral imaging studies such as a magnetic resonance imaging (MRI). Although focal or partial seizures may remain localized until they cease, it is not uncommon for focal or partial seizures to become generalized seizures. Many become generalized so quickly that the caregivers usually do not notice the initial focal manifestations of the seizures. However, other focal seizures become generalized after an appreciable time has elapsed. Generalized seizures begin with a widespread, bilateral, and synchronous hemispheric involvement. Epileptic seizures may be convulsive or nonconvulsive in nature, depending on where in the brain the malfunction takes place and on how much of the total brain area is involved. The following classification of seizure disorders is based on the *1981 International Classification of Seizure Disorders.*

Partial Seizures

Simple Partial Seizures. In simple partial seizures, the consciousness of an affected individual is not impaired and the individual can interact normally

with the environment except for those limitations imposed on specific functions by the seizure.

Simple partial seizures can be classified into the following groups: (a) with motor signs such as focal motor without march (i.e., seizures remain localized until they cease); focal motor with march (i.e., body parts are often initially involved distally, and then more proximal portions are involved); versive, postural (the eyes and head turn to one side and at times the patient gazes at the hand of that side), and phonatory (vocalization or arrest of speech); (b) with somatosensory symptoms (e.g., tingling or pins-and needles sensation) or special-sensory symptoms (e.g., visual light flashing taking the forms of zig-zag lines, circumscribed circles, squares, stars, or animals that appear smaller than actual size; auditory buzzing, loud swishing noises, and other easily recognized, complex auditory hallucinations; olfactory-, gustatory-, and vertiginous-tornado fits); (c) with autonomic symptoms or signs (e.g., epigastric sensation, recurrent abdominal discomfort and vomiting, pallor, sweating, flushing, salivation, piloerection, and pupillary dilation); and (d) rarely with psychic symptoms (e.g., dysmnesic symptoms including distortion of memory or time, flashback experiences, deja vu, or occasionally experiencing a rapid recollection of episodes from life; cognitive disturbances including dreamy states, sensations of extreme pleasure or displeasure involving feelings of fear and intense depression, and rarely with anger or rage, distortions of time sense; illusions—objects appear deformed in size or shape; structured hallucinations—sounds of voices, music, scenes; Dreifuss, 1989; Pedley & De Vivo, 1991).

Complex Partial Seizures. When consciousness is impaired, the seizure is classified as a complex partial seizure (also called psychomotor or temporal lobe seizure). Impairment of consciousness may be the first clinical sign of complex partial seizures. However, in some cases, complex partial seizures may be evolved from *simple partial seizures.*

The main feature of the complex partial seizures varies, but they usually include impairment or alteration of consciousness (occurring either near the beginning or during the seizure attack), unresponsiveness, and automatisms including repetitive, complex motor activities that are purposeless, undirected, and inappropriate to the situation. Examples of automatism include lip smacking; repetitious swallowing or chewing; fidgeting movements of the fingers or hands; gestural movements such as clapping or scratching, picking up objects, fumbling with or picking at clothing; trying to take clothes off; walking or riding a bicycle with an appearance of either being goal directed or completely disorganized; appearing unaware of surroundings or dazed; stereotyped verbal response to stimulation; or repetitive utterance or mumbling. Psychoillusory phenomena may be reported at the onset of an attack, including a sense of detachment or depersonalization,

forced thinking, visual distortions and formed hallucinations, visceral sensations, and a feeling of intense emotions such as fear, loneliness, depression, sadness, anger, joy, or ecstasy. At times, fear during a seizure may lead to running away.

Once a pattern of complex partial seizure attack is established, the same set of actions usually occur with each seizure attack that lasts a few minutes. Immediately after the seizure attack, individuals are confused and recover full consciousness slowly. During a time of incomplete awareness they may resist restraint and react aggressively or angrily to objects and persons in their way. However, rage attacks or temper tantrums do not occur as manifestations of epilepsy. The individuals do not have any memory of what happened during the seizure attack.

Generalized Seizures

Tonic–Clonic Seizure. *Tonic–Clonic seizure* (also called grand mal seizures) is characterized by abrupt onset with immediate loss or alteration of consciousness and an abrupt fall. During tonic phase, forced expiration against a partially closed space in the vocal cords often leads to a hoarse cry. There are massive sustained contractions of the entire musculature with limb extension and back arching (a stiffening of the whole body), trismus, shallow breathing or temporarily suspended breathing, and eyes deviated conjugately upward. There are marked autonomic phenomena including pupillary dilatation, salivation, diaphoresis, and dramatic rises in blood pressure and heart rate to two or three times normal levels. Often there is urinary incontinence, and sometimes there is fecal incontinence as well. This tonic phase lasts from several seconds to several minutes, and cyanosis develops. Tonic phase is followed by clonic jerking with the head retroflexed. The arms are usually flexed, and the lower extremities are extended. The clonic phase can continue for minutes, waxing and waning. In most instances the clonic phase gradually subsides as the jerks decrease in frequency. After the clonic phase, the patient regains full consciousness slowly and is typically confused and excessively somnolent for minutes to hours after an attack. When fully awake, the patient may complain of headache and muscle pain but is otherwise amnesic for the events surrounding the seizure.

Absence Seizures. *Absence seizures* (also called petit mal seizures) manifest as momentary lapses in awareness with amnesia. They begin and end abruptly, rarely lasting more than a few seconds. There is no warning or postseizure attack period. Sometimes attacks are so brief that they escape detection. The individual having the seizure is unaware of what is going on during the seizure, but quickly returns to full awareness once it has stopped.

In a typical absence seizure attack the patient abruptly loses consciousness, ongoing activity ceases without significant alteration in postural tone, and the individual's eyes stare vacantly straight ahead or may roll upward. There is no movement except possibly some subtle fluttering of the eyelids or eye blinking, twitching of the perioral muscles, or some chewing movement of the mouth. Other common features are autonomic phenomena such as pupillary dilatation, change in skin color, tachycardia, piloerection, and automatisms (aberrations of behavior). At the end of the seizure the individual suddenly resumes previous activity as if nothing had happened, without any postictal confusion or drowsiness. Dozens to hundreds of seizures may occur in a single day. Some children with absence seizures may have seizure attacks when exposed to flashing or flickering lights, black-and-white patterns that strobe, and certain intense flashing effects in videogames.

Absence seizure is one of the benign forms of childhood seizure, which usually responds well to treatment with AEDs and may disappear at adolescence.

Atonic Seizures. *Atonic seizures* (also called drop attacks) occur, for example, when the legs of a child between 2 and 5 years of age suddenly collapse and the child falls. After 10 seconds to a minute the child recovers, regains consciousness, and can stand and walk again. Atonic seizures are often mistaken for clumsiness, lack of good walking skills, or normal childhood "stage."

Myoclonic Seizures. *Myoclonic seizures* manifest as sudden brief, massive muscle jerks that may involve the whole body or parts of the body. They may cause a person to spill what they are holding or fall off a chair. Sometimes these become generalized tonic–clonic seizures. Adolescence may be a time when this type of seizure disorder (called juvenile myoclonic epilepsy) begins. Juvenile myoclonic epilepsy also responds well to treatment, but the seizures usually return when medication is discontinued.

Other Seizure Disorders

Infantile Spasms. *Infantile spasms* are a rare form of epilepsy that affects children in a narrow age range, starting between 3 and 12 months and stopping at age 2 to 4 years. These children may experience developmental delay and go on to have other types of seizures later on. About 1 in 10 of them also develops Lennox–Gastaut syndrome.

Lennox–Gastaut Syndrome. *Lennox–Gastaut syndrome* typically begins between 1 and 6 years of age and includes mixed seizures such as convulsions,

myoclonic seizures, and drop attacks (atonic seizures). Children with drop attacks may have to wear helmets to protect their faces and heads from the effects of these frequent falls. Children with Lennox–Gastaut may have developmental delays as well as other neurological challenges.

Management of Seizure Disorders

Effective treatment can be achieved if an accurate early diagnosis of seizure type can be established. It is essential that the nonphysician caregivers provide a thorough and accurate history including (a) a description of the characteristics of the attack including age of onset, date and circumstances of first attack, one or more than one seizure type, manifestations of seizure attack(s), postictal manifestations, any change of seizure pattern, any recognizable precipitating or associated factors, frequency of attacks, and longest seizure-free interval; (b) a pertinent past history including details of birth, postnatal course, and early development, serious illness, trauma, ingestions or toxic exposures, reactions to immunizations, and school performance; and (c) a relevant family history (e.g., other family members with a seizure history). The physician will then perform a thorough physical and neurological examination on the individual and order some selective laboratory studies. An EEG should be done in every individual who has seizures. A MRI scanning will be considered in individuals with abnormal neurological examination or focal slow-wave abnormalities on the EEG. In some uncertain or confusing cases, a period of watchful waiting will often clarify the diagnostic question.

Effective treatment of an individual with autism and seizure requires active interactions among multiple factors including medical, psychological, and environmental factors. Nonetheless, these individuals are likely to require long-term anticonvulsant treatment. The selection of the medication for the treatment depends on the type of seizure (Table 12.1), and the use of medications is best managed by a neurologist specializing in seizure disorders.

In general, management of seizures in individuals with autism is the same as that in epileptic patients without autism. However, when psychotherapeutic medications are considered in persons with both autism and seizure disorder, the potential alterations in seizure threshold and the interactions between psychotherapeutic medications and anticonvulsants should be assessed.

Medication Treatment of Seizure Disorders

In the past, if a child had a seizure, medication was immediately prescribed. This was done out of concern that great harm could result by permitting the child to have additional seizures. It is clear now that such a

concern is essentially unwarranted. Physicians are now better able to advise families concerning the risks and benefits involved in refraining from medication treatment for the child who has experienced a seizure. Various studies have shown that individuals may have a single seizure and never have a recurrence. Hence, the chronic use of potentially toxic medication to prevent something that may never happen is unwarranted.

On the other hand, the chance of recurrence after a single nonfebrile seizure ranges from 30% to 80%. Few individuals would have a risk of recurrence higher than 80%. It has been estimated that a cumulative risk of seizure recurrence was about 40% at 48 months. If the seizure was considered idiopathic and generalized, and if the EEG was normal, the cumulative risk of recurrence was about 25% at 36 months. On the other hand, if the seizure was symptomatic (presumably of a previous CNS insult such as trauma or CNS infection), cumulative risk of recurrence was about 60% at 36 months.

The consequences of a recurrence seizure vary with age. In a young child who is generally well supervised, the consequence of recurrence may be small because it is unlikely that the child will be seriously injured if another seizure occurs. But an older more independent individual who is farther from home on a bicycle or driving a car may be at a greater risk. This aspect of the decision making must be carefully individualized.

The most common forms of childhood epilepsy respond best to treatment and are also most likely to be outgrown. They are familial neonatal epilepsy (seizures in newborns), febrile seizures, absence seizures, and benign focal epilepsy. These disorders sometimes are described as "benign epilepsies of childhood" and they occur in children between the ages of 2 and 13. Children with these benign epileptic syndromes respond well to single AED and are able to live an active, normal childhood. They are often able to discontinue the medicine after they have been seizure free for 2 years. At that time, physicians may recommend a slow tapering off and an eventual withdrawal of the medication. About 65% to 80% of children with this type of epilepsy will continue to do well, with no further seizures after the AEDs are withdrawn. If seizures return, medication is resumed. Usually, it is as successful in controlling seizures as it was before.

The objective in the treatment of the seizure disorder is a complete control of seizures, or at least a reduction in their frequency to the point where they no longer interfere with physical and social well-being. It is not uncommon that a single AED is all that is needed to achieve satisfactory seizure control in individuals with seizure disorders. In some cases, complete seizure control may not be possible. The acceptance of the occurrence of an occasional seizure is more appropriate than using multiple AEDs for prolonged periods which tend to cause cognitive and behavioral side effects in persons with seizure disorders. If the risks of therapy outweigh the possible benefits, caregivers should be more understanding of the decision to refrain from

therapy when the likelihood of recurrence is small or when seizures are infrequent.

Factors in Drug Choice. Prescribing medication for epilepsy is as much an art as it is a science. For either medical or social reasons, some individuals may prefer or be better suited by one medication over another. Once a seizure disorder has been diagnosed and a decision to use AED to control the seizures is made, the appropriate AED should be considered. Various factors including seizure type, age, neurological function, and social circumstances are involved in deciding which AED should be recommended as initial therapy. The individual and his or her family may have limited access to medical care, limited funds, and there may be a problem in administering medications multiple times a day. In that situation an AED that is inexpensive and can be taken once a day may be considered first. It is the right medication if seizures are controlled and the individual continues to feel well and perform at his or her maximum ability. If there are adverse changes in function, then it is probably the wrong medication, in spite of cost and ease of administration, and the medication should be changed. Each individual medication has the potential for causing different side effects. The choice of AED should be based on seizure type balanced with the risk of acceptable side effects. For example, Dilantin is an excellent AED for a variety of seizure types. Because of its potential for cosmetic side effects such as gum hypertrophy and excessive hair growth, its use by adolescents and teenagers may be reconsidered if another suitable medication can be used.

General Guidelines to AED Therapy

1. Treatment should begin with one AED. If the AED does not control seizures, it is discontinued gradually while a second AED is instituted and its dosage is increased.
2. Alterations in drug dosage should be made gradually, usually not more frequently than once every 5 to 7 days until seizures are controlled or until clinical toxicity is seen.
3. On occasion, a person will not respond to an AED commonly used for his seizure type. When this occurs, the physician should determine if the type of seizure has been misclassified. If an error in seizure classification is uncovered, appropriate changes in the medications can be made.
4. Once seizures are controlled, the medication should be continued for a prolonged period of time.
5. If your child has infrequent seizures, the medication can be increased gradually until the blood level of the AED reaches the lower end of the therapeutic range of that AED. The dosage should be increased subsequently only if there is seizure breakthrough.

6. Determinations of anticonvulsant blood levels are necessary in all cases. Monitoring of blood levels is very useful as a guideline to indicate subtherapeutic levels and possible problems with compliance. Blood levels also serve as a guideline of impending toxicity. In more complex situations (e.g., polytherapy) blood levels may help determine which medication is more likely to be responsible for toxicity.

7. Anticonvulsant medication should be withdrawn gradually.

8. When psychotherapeutic medications are considered, the interactions between psychotherapeutic medications and AEDs should be carefully assessed because there is a possibility of an alteration in seizure threshold which can induce seizure activities even in individuals with a previously well-controlled seizure disorder.

9. When adverse changes are observed in the child's cognitive and emotional functioning while he or she is on AEDs, the child's doctor should be informed. If there are no other alternative explanations for the neurobehavioral effects, the dose of the medication should be reduced, or the medication should be changed if the former approach does not produce significant improvement of the adverse changes.

Alternatives to Medication Treatment

Several options exist for the person who continues to have seizures despite treatment with various medications. These include:

Experimental AED. The FDA does not currently approve these medications for marketing, but they may be available at certain epilepsy research centers. However, a child must first qualify as a suitable candidate under specific criteria defined by the study's objectives. He or she may be excluded from the study if his or her seizures are of a different type from those being investigated. Once enrolled in a study, there are often strict protocols that must be followed as part of the research, such as having frequent blood work performed and filling out questionnaires.

Ketogenic Diet. This is a special diet that consists primarily of foods rich in fat and low in carbohydrates and proteins. In the body, these fats are metabolized and form a product called ketones. For reasons not completely understood, the presence of these ketones seems to have a protective effect against seizure activity. However, this diet is very difficult to administer due to unpalatable taste, its requirement of meticulous measuring and weighing of foods, and urine testing to ensure appropriate ketone levels.

The Vagus Nerve Stimulator. This is a device recently approved by the FDA for the treatment of epilepsy. The vagus nerve is the longest nerve in

the brain. It is a major communications channel from the brainstem to the neck, throat, chest, and abdomen. Similar to a pacemaker, the vagus nerve stimulator is implanted under the skin and sends small electrical impulses to the vagus nerve. For reasons currently under investigation, this repeated stimulation appears to reduce the frequency of seizures in some individuals who receive such a treatment.

Epilepsy Surgery. Two criteria are generally required for epilepsy surgery. The first is that a person's seizures all arise from the same part of the brain. The second is that this area of the brain not be involved in an important function such as speech, movement, or recognizing sensations. The goal of epilepsy surgery is to remove the epileptic focus (the part of the brain causing the seizures) while preserving normal function. A complex, extensive presurgical investigation including video-EEG monitoring and recording of several seizures are done by an epileptologist to pinpoint the part of the brain to be operated on by the neurosurgeon. After this evaluation, if all of the person's seizures are found to arise from a single focus, surgery is considered as a potential option.

SUMMARY

An overview of medical treatment, particularly of pharmacotherapy in individuals with autism and related disorders, is presented. Recent advances in medication treatment in autism and other childhood psychiatry disorders are highlighted. Just as aspirin can reduce a fever without clearing up the infection that causes it, the medication treatment of autism acts by controlling symptoms. Persons with autism are treated with psychotherapeutic medications for the maladaptive behaviors that may develop during the course of their lives, as well as for the symptoms that may be caused by underlying or coexisting neuropsychiatric disorders. However, the target symptoms and maladaptive behaviors in persons with autism are viewed as results of these individuals' inability to cope with the environmental demands and physical discomfort, as well as their suffering from disturbed neurochemical and neurophysiological functions. Further, the use of medications in this population is viewed only as one component of a comprehensive treatment plan for persons with autism. Some existing clinical data suggest that with an appropriate evaluation, premedication workups, a specific diagnosis, and multiple measures of outcome, pharmacotherapy is a safe and efficacious treatment for some symptoms in persons with autism. The data presented in this chapter, however, were obtained mainly from children with autistic treated with neuroleptics and some SRIs. A great deal of work remains to

be done with other drugs as well as with adolescents and adults with autism. Future research should also place more emphasis on studying the efficacy of combined treatments such as pharmacothery with behavioral therapy, or group therapy with medication therapy.

However, we now stand at the threshold of a new era in brain and behavioral sciences. Through research, we will learn even more about neuropsychiatric disorders including autism. And we will be able to use this knowledge to develop new interventions including psychopharmacological therapy that can help to minimize the autistic individual's maladaptive behaviors (e.g., self-injury and aggressiveness) and neuropsychiatric symptoms (e.g., tics, hyperactivity, compulsive behaviors, anxiety, and depression) which interfere with or are incompatible with the individual's functioning and learning. Such an approach can enhance more normal social and communicative developments in persons with autism.

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Chapter 13

Community Integration and Supported Employment

Marcia Datlow Smith
Leslie R. Philippen
Community Services for Autistic Adults and Children, Rockville, Maryland

INTRODUCTION

David Markham awakens each weekday morning at 7:00 a.m. He washes, dresses, prepares and eats breakfast. At 8:00 a.m. his ride comes, and he leaves for work. Mr. Markham works for a company that prepares snack-food trays for vending machines. He sorts the items and places them in their designated bins in the trays.

Mr. Markham has a high level of productivity. In fact, he works faster than most of his co-workers. He earns minimum wage, and is slated for a raise in the near future. Mr. Markham seems to enjoy his work. He is a quiet worker who keeps to himself and is not given to leaving his work station to exchange idle gossip with co-workers.

In most respects, Mr. Markham does not differ from many other American workers. However, in one respect Mr. Markham is quite different from his co-workers. Mr. Markham is severely disabled by autism. He has no verbal language. His intelligence is considered to be in the severe range of mental retardation. He also has a history of severe self-abuse, including high—intensity head banging.

The circumstances of Mr. Markham's life probably more closely resemble those of his nondisabled co-workers than those of other individuals who bear his diagnosis. Unlike most individuals with autism, Mr. Markham enjoys full community integration. His neighbors are nondisabled, as are his

co-workers. He dines, shops, vacations, and enjoys his free time alongside the other nondisabled citizens in his community. And, he has been able to work for all of his adult life with the assistance of a job coach provided by a supported employment program.

Community integration has not eliminated Mr. Markham's autism. But neither has autism eliminated integrated work and living experiences from Mr. Markham's life options. This chapter explores community integration and supported employment for individuals with autism.

INTEGRATED COMMUNITY LIVING

Integrated community living can be an option for all individuals with autism (Schreibman & Anderson, 2001). Autism need not dictate the neighborhood within which the individual can settle. Autism simply dictates the amount of support services necessary to achieve community adjustment. There are several models for integrated community living that can be utilized by people with autism.

Living With Family

In many cultures, and across many periods of history, extended family units were not the exception, but the rule. Several generations lived under one roof, and as the family enlarged, so did the size of the dwelling. During periods of economic or domestic stress in our current culture, adult children may move back in with parents. Certainly, living with their parents is a viable option for some adults with autism and their families (Marshall & Mirenda, 2002; Vaughn, Wilson, & Dunlap, 2002).

Living With a Foster Family

For some individuals with autism, a foster family situation can be an option. Many states sponsor specialized foster care programs for people with developmental disabilities. These are typically specially licensed homes, with caregivers receiving training in developmental disabilities.

The behavior management issues that can be associated with autism can make foster care placement difficult. Family foster care is usually provided for people with mental retardation who do not have serious behavior problems (Hayden, Lakin, Hill, & Bruininks, 1992). The provision of support services and specialized training to the foster family provider can make this a viable option for some adults with autism.

Independent Living

Some adults with autism can live in their own home with little or no support from family or other agencies. Minimal support might be needed. Support might be in the form of drop-in assistance for shopping, budgeting, and meal planning. Support can also be provided to help the person make social decisions and deal with challenging social situations. If an adult has challenging behaviors, such as self-injury or aggression, then more support than drop-in support would be needed.

Partially Supported Living

Some individuals with autism, because of communication, social, or skill deficits cannot live independently. However, the effects of the disorder might be sufficiently mild so that the individual can live in a supported living situation in which partial assistance is available.

One option is to have an individual with autism living with one or two roommates without disabilities, who can provide some assistance with the activities of daily living, as necessary. These individuals may or may not be paid for their assistance.

Another option is to have a living arrangement in which the support is provided for some, but not for all of the hours of the week. Support might be provided at important times, such as in the mornings before work and in the evenings around dinner time. This arrangement of partial supervision is possible for individuals who do not have severe behavior problems and who do not require assistance on an around-the-clock basis.

Fully Supported Living

Fully supported living arrangements, when not provided by family or foster families, can be provided through small group residences. One or several individuals in need of 24-hour support live together in a house or apartment, under the supervision of paid staff. Staff provide ongoing assistance with the activities of daily living. Staff can also help with social skills and behavior management if needed.

CRITICAL COMPONENTS FOR COMMUNITY LIVING

Residential situations for adults with developmental disabilities should include adequate physical care, personal and social relationships, leisure and recreational activities, habilitation programming, and respect for human

rights (Holburn & Vietze, 2002). Because autism also includes problems with language and behavior, there are aspects of care that merit special attention.

Supervision

The amount of supervision can be critical for successful community integration. An individual with mental retardation who does not have challenging behaviors might suffer from lack of supervision by evidencing poor grooming and hygiene and other disquieting, but not necessarily devastating, signs of neglect. An individual severely disabled by autism, even with above-average intelligence, can suffer devastating consequences from inadequate supervision.

Autism is a disorder of behavior, and so can be accompanied by challenging behaviors that can be destructive in nature, including property destruction, aggression, self-injury, and pica. Failure to provide adequate supervision can result in significant property destruction, injuries ranging from bruises to head injury to the individual, and the eating of inedible objects, which can include glass and metal. Lapses in supervision can be life threatening and harmful to others. These outcomes not only put the community placement at risk but also jeopardize the life of the individual. Increased supervision can be provided in a group home setting by the assignment of additional staff. In a family or foster care situation, the provision of additional supervision in the form of part-time aides can help to ensure safety in the placement.

Participatory Living Situation

Even those individuals who are most severely disabled by autism can participate at some level in their activities of daily living, home care, and self-care. Many of the challenging behaviors that can be associated with autism, including self-stimulation, aggression, self-injury, and property destruction can be significantly reduced through an enriched environment, which provides ample opportunity for full participation in meaningful tasks (Freedman & Boyer, 2000; Smith & Belcher, 1992).

The living situation of an individual with autism should include an active daily schedule, in which the individual participates fully in self-care, home care, food planning, food preparation, and all activities that are necessary for the maintenance of the home and the individual. Individuals who are less disabled, and more independent, can participate in these activities independently or with minimal assistance. Individuals who are severely disabled by autism, who may have severe mental retardation and no verbal skills,

may need ongoing assistance and supervision (Center for Autistic Children, 2000). However, such needs should not preclude participation. The opportunity for full participation at home is critical to community adjustment, because in itself it is a substantial deterrent to the destructive behaviors that can be so threatening to an integrated community lifestyle.

Recreation and Leisure

Recreation and leisure activities are crucial for good mental health of people with developmental disabilities (Wilson, Arnold, Rowland, & Burnham, 1997). For individuals with autism, such opportunities can be key to successful community integration. Participation in recreation and leisure activities, like full participation in home and self-care, can be helpful in the management of behavior and communication problems that can be associated with autism (Schneiter & Devine, 2001).

There is a growing body of research that suggests that self-simulation, and even self-injury, can be prevented by the provision of alternate sensory stimuli (Smith, 1986b; Smith & Belcher, 1992). Recreation and leisure activities can be seen as the ultimate in alternate sensory stimuli. Such activities are incompatible with the withdrawal and self-stimulation that can be associated with autism. Designing enriched daily schedules which include these activities can be incompatible with more destructive behaviors as well, such as self-injury and aggression. Providing choice and enough supervision is important for an individual's success.

A young man with autism might enjoy playing in the toilet. The local swimming pool provides a natural source of alternate, and more acceptable, sensory stimuli. A young boy with autism has life-threatening darting behavior. Unless a staff person holds his elbow or his backpack, he is likely to dart away, unmindful of oncoming vehicles. Frequent excursions to the park or local track, where this boy can freely run and bolt, provide an alternate and more acceptable form of stimulation.

Ideally, recreation and leisure activities should be integrated, normalized experiences. The individual with autism attends with an assistant, if necessary, and participates with nondisabled individuals. These activities should be age appropriate and, when possible, allow for personal choices. These experiences not only provide the stimulation of the activity but also have the advantage of normal role models. Swimming, movie going, horseback riding, fishing, boating, hiking, road trips, and even participation in aerobics classes are only a few examples of activities that can be enjoyed by an individual with autism.

For many individuals with developmental disabilities, autism included, recreation and leisure experiences can improve the quality of life and lead

to integrated community living. Additionally, for people with autism who also have challenging behaviors, recreation and leisure activities can play a unique role in the management of these behaviors. These experiences are not simply enhancing; they can be critical for maintaining community adjustment.

Behavior Management

Many individuals with autism can enjoy productive home lives if supervised by caring people, and if provided with full participation in home care, self-care, and recreation and leisure activities. However, for some, challenging behaviors can be so destructive that they appear to prevent full participation. Self-injury and stereotypic behaviors become a deterrent to task presentation. Staff or parents can become reluctant to place demands, for fear that the individual will begin head-banging in order to escape the undesired task. Aggression becomes an obstacle to trips to the restaurant, and property destruction appears to preclude shopping. Again, staff or parents can fear taking the person out because of the aggression or property destruction that might occur. In fact, protecting the society from the menaces of the individual with disabilities was a justification for the institutionalization of these individuals (Wolfensberger, 1975).

If Johnny has an incident of throwing his soda in McDonald's, his group home staff will fear returning to McDonald's. If Sandy has an incident of attacking her mother at the mall, her mother, understandably, will fear returning to the mall. If Becky hits her head at her new supported employment job, her supporting agency might fear returning her to work. What can happen, then, to the persons with autism and behavior problems, whether living with parents or even in a group home, is that their world becomes smaller and smaller as caretakers fear leaving the house with them.

Behavior management has had demonstrated effectiveness in each setting in which it has been applied, since its inception in the laboratory, through segregated settings, and in the 1980s and the 1990s, in integrated community placements (Marquis et al., 2000; Rosenwasser & Axelrod, 2001). Behavior management has been successfully applied to behaviors that have been obstacles to community integration, such as self-injury (Belcher, 1994; Smith, 1990), aggression (Belcher, 1994; Carr et al., 1999; Jensen, McConnachie, & Pierson, 2001; Smith, 1986), pica (Hagopian & Adelinis, 2001; Piazza, Roane, Keene, Boney, & Abt, 2002; Smith, 1987), and property destruction (Belcher, 1995; Smith, 1990).

Behavior management can be an important part of home adjustment. An effective behavior management plan typically includes an environmental analysis, a functional assessment of the behavior (Kemp & Carr, 1995), and

interventions that teach or reward more appropriate behaviors (Ringtail et al., 2002; Kransny, Williams, Provencal, & Ozonoff, 2003), remove or mitigate setting events, and enrich the environment (Horner, 1980; Smith & Belcher, 1992).

Because the most devastating impact of autism can be the associated behavior problems, careful environmental design done using a behavioral approach can be a key element in residential success. Lack of good behavior management procedures can result in well-meaning caregivers actually promoting the very behaviors that they wish to eliminate. And, if this is the case, even the best supervisory ratios will not overcome the behavioral effects of the disorder. Well-planned behavior management can make efficient use of caregiver time by preventing or minimizing the effects of behavioral crises through promoting a positive, nonaversive, but properly structured environment.

Support Services

Individuals with autism living in the integrated community setting need many of the same supports that their neighbors without disabilities need. Medical, dental, counseling, psychiatric, and other speciality services may be needed. These services are best utilized when they are tailored to the individual's specific needs (Smith, 1990).

Although many individuals with autism do well without psychotropic medication, some individuals benefit from this course of treatment. People with autism might have depression, anxiety, or other symptoms of mental illness that respond well to pharmacological treatment (Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Luiselli, Blew, & Thibadeau, 2001). In fact, those symptoms might be a factor in destructive behaviors that might occur. Unfortunately, treatable symptoms of mental illness are often not diagnosed in people with autism. New medications and more effective use of psychotropic drugs by skilled psychiatrists can improve the quality of life for many people with autism (Barnard, Young, Pearson, Geddes, & O'Brien, 2002). When used along with behavior programming, significant improvements in behavioral functioning can also be realized. Treatment can be facilitated by a psychiatrist with expertise in autism who is willing to work closely with the family or caretaker on carefully evaluating data on those behaviors or symptoms that are targeted by the medication (Volkmar, 2001). Behavioral support services can be critical, particularly in cases in which the individual exhibits self-injury, aggression, or property destruction. Specific behavior management strategies are chosen based on a functional assessment to meet the behavioral challenges of the individual. Behavior support services might need to be long term or ongoing, so that the behavior plan implementation

and progress can be carefully monitored, and adjustments can be made as necessary.

Donnellan, LaVigna, Zambtio, and Thvedt et al. (1985) reported on a time-limited intervention program model to support community placement for people with severe behavior problems. Specialists provided behavior intervention within home settings, and were able to achieve significant improvement in those settings.

Speech and language services, particularly augmentative communication techniques (Ogletree & Harn, 2001; Ogletree & Oren, 2001), occupational therapy (Watling, Deitz, Kanny, & McLaughlin, 1999), physical therapy, and nutritional consultation might all be useful supports to an integrated community lifestyle. Dunn (1991) discussed three models for providing related services, all of which can be applicable to supporting individuals with autism. The *direct therapy model* involves specialists who provide direct therapy to the individual. The *monitoring model* involves a specialist who monitors the implementation of strategies within the home setting, but remains primarily responsible for outcomes. The *consultation model* utilizes a therapist who serves as consultant to the caregiver, who bears the primary responsibility for outcome.

A critical feature in the provision of related support services to individuals with autism is that the service be directly applicable to problems within the individual's daily life. Individuals with autism have difficulty generalizing, and this difficulty places limits on the usefulness of therapy which is not directly integrated in and applicable to the individual's daily routine. Research on naturalistic language therapy is a good example, with several studies pointing to the superiority of language activities within the natural environment (Ogletree & Harn, 2001).

Parents or foster parents who are living with individuals with autism might need additional support services, such as part-time assistants within the home, or respite care, which allows the primary caregiver time off. For individuals with destructive behaviors, or chronic sleep problems, in-home support in the form of an aide or relief staff can make remaining in the community a reasonable alternative to moving individuals out of their homes to more segregated settings. Families of individuals with developmental disabilities can also benefit from additional support services, including stress management, parenting skills training, support groups, and community-based respite care.

SUPPORTED EMPLOYMENT

The behavior problems associated with autism have historically been considered incompatible with employment. Kanner, Rodriques, and Ashenden (1972) found that only 10% of a sample of 96 children diagnosed with autism

at Johns Hopkins Hospital prior to 1953 were "sufficiently integrated into the texture of our society to be employable" (p. 10). Since that time there has been increased attention to improving employment opportunities for people with disabilities. Supported employment has increased dramatically from 10,000 participants in the mid-1980s to 105,000 in the early 1990s (Parent, Kregel, & Johnson, 1996). Despite these promising figures, people with severe disabilities only constitute about 12% of all people with mental retardation placed in nationally supported programs (Wehman & Targett, 2002). Further, Certo et al. (2003) noted that adults with disabilities had no better employment rates than they did 20 years prior.

Studies have shown that adults with autism have been able to achieve and maintain employment through supported employment programs (Keel, Mesibov, & Woods, 1997). Many people with autism have been able to work at competitive, nonsheltered employment with the help of specialized support on the job. Smith, Belcher, Juhrs, and Nabors (1994) reported on 12 years of supported employment in which adults disabled by autism held 381 jobs, some of which required specific skills traditionally not expected of people with severe disabilities. Certo et al. (2003) have presented a model for transition students with severe disabilities and high support needs into supported employment programs in which they are able to maintain employment following graduation.

Workers with autism have been employed in a variety of settings. Successful careers have been found in manufacturing firms, warehouses, retail stores, libraries, recycling centers, vending machine suppliers, solar energy development, electronic firms, laboratories, and county and federal government agencies (Smith, Belcher, & Juhrs, 1995).

Models of Supported Employment

Supported employment is provided to the individual with a disability by a habilitation agency that provides support in the following five ways: finding appropriate jobs, placing the individual in a job, on-the-job training, ongoing assessment of performance, and implementing procedures to ensure long-term job retention (Wehman, Parent, Wood, Kregel, & Inge, 1989). The support may also be in noninstructional areas, such as developing relationships with supervisors and co-workers, providing information and training to supervisors and co-workers, and encouraging socialization between the worker and co-workers. Chadsey and Beyer (2001) describe the importance of close social relationships as they positively influence job satisfaction and decreased stress levels.

The degree of support that may be necessary is dictated by the needs of the individual. Similarly, the manner in which the support is given is also individually determined. These supports will be described in the context of

an individual with autism working at a community business, possibly with one or two other workers with autism.

There are several models of support for the worker with autism. The most common is the *job coach model.* The job coach is typically an employee of a human services organization and is responsible for teaching the individual the job, and managing any instructional, behavioral, or interpersonal issues that may arise at work.

Employers and co-workers of individuals with developmental disabilities in supported employment programs have given those workers favorable ratings and have said they value the training provided by supported employment service providers (Olson, Cioffi, Yovanoff, & Mank, 2001). Further, Test, Carver, Ewers, Haddad, and Person (2000) conducted a study on longitudinal satisfaction with supported employment jobs and services and found that participants were consistently satisfied with both their jobs and the services provided by their job coaches.

Nisbet and Hagner (1988) proposed alternatives to the job coach model, which rely primarily on supports that are naturally occurring in the work environment. These authors propose consideration of a *mentor model,* in which the job coach does the initial training, and a co-worker assumes the role of mentor and subsequent responsibility for the worker; the *job sharing model* in which the worker shares a job with a nondisabled person who also assumes some of the responsibility of providing support; and the *training consultant option,* in which a consultant from a human services agency provides training to co-workers at the site who in turn support the worker with the disability. Cimera (2001) reported that although the use of natural supports did not increase the cost efficiency of supported employment services, it did increase tenure on the job by over 1 year.

The model used may be dictated by the amount of support the worker with autism needs and the nature of that support. Degrees of support and the length of time such support is needed are reviewed in the following pages.

Full-Time, Long-Term Support

Some individuals with autism may need full-time, long-term support. These are most likely individuals with severe autism, no verbal language, mental retardation, and a history of destructive behaviors, such as property destruction, aggression, pica, or self-injury, and a great deal of difficulty remaining in the work area and on task. These workers may need continual supervision to ensure their own safety and the safety of co-workers. The support person might need to manage the destructive behavior by the implementation of intensive behavioral programming. Gray, McDermott, and Butkus (2000)

investigated the effects of job coaches and found that the likelihood of employment was approximately two times greater for individuals with low IQs than for individuals with high IQs.

Some behavior problems, despite proactive behavior management, might present some ongoing level of danger to the workers and others if not expertly managed. Because of the behavioral needs, and risk of behaviors such as property destruction, aggression, and self-injury, some workers with autism will require constant long-term supervision despite higher levels of intellectual and language functioning.

The use of the mentor model or the trainer-consultation model might not be realistic for some adults with autism, because of the intensive amount of supervision required. The mentor would have little or no time left to attend to other job duties. The traditional job coach model might be dictated for these individuals.

Partial Support

Some individuals with autism can succeed with less than full-time support. Individuals with sporadic behavior problems (e.g., every few months), or with fairly significant social skill deficits that require daily or weekly training, may need some level of support indefinitely; however, part-time monitoring might suffice (Smith, 1985). Parsons, Reid, Green, and Browning (2001) found that job coach assistance can be reduced for adults with severe multiple disabilities by providing off-work site training that focuses on those work skills requiring job coach support.

Individuals with autism who need only partial support may be the most promising prospects for the use of supports within the natural environment (Unger, Parent, Gibson, Kane-Johnston, & Kregel, 1998; West & Kregel, 1997). The mentor model or trainer-consultation model (Nisbet & Hagner, 1988) provides an efficient and natural way to serve these individuals. Individuals who only need occasional assistance, or sporadic social skills or instructional training, can obtain such training from co-workers. Co-workers and supervisors can play crucial roles in facilitating job success (Unger, 1999). Co-worker involvement along with a job coach can vastly improve outcomes (Mank, Cioffi, & Yovanoff, 2000).

Temporary Supports

Some individuals with autism may need help only in finding a suitable job match. Once the job is found, the worker with autism may be able to go to work independently and benefit from the same on-the-job training that nondisabled workers receive.

Other workers with autism may have special learning needs that require temporary support in the form of initial instruction and assistance with integration into the worksite. For these workers, temporary support might be sufficient. Once they have learned the routine and tasks, and have become familiar with the co-workers and social expectations of the site, supports that were once full time can be gradually withdrawn (Mautz, Storey, & Certo, 2001).

Even individuals with challenging behaviors can look forward to partial or even complete independence on the job. Some individuals with autism have specific social skill deficits that can be minimized by the type of job held. For example, a lack of social skills is not critical if the individual works in a stockroom and has little social interaction as part of the job duties. If the individual is placed in a job in which the individual's deficits are not job threatening, then support can be quickly and possibly permanently faded.

Once the individual has learned the requirements of the job and performs satisfactorily and reliably, the job coach or mentor can fade back to occasional drop-in visits or interventions. When behavior problems are not destructive in nature, or when such behaviors have been reliably eliminated, the fading of supports can be a realistic option.

CRITICAL ELEMENTS OF SUPPORTED EMPLOYMENT

There are several elements that are critical to the successful employment of workers with autism. A major issue is the amount of support. The intensity of support and length of time that support is available are both critical to job adjustment.

Supervision

The provision of sufficient supervision is a critical element in achieving and attaining employment for people with autism. Failure to provide sufficient supervision from the outset, or withdrawal of supervision for some individuals with autism, would not only be job threatening for a number of individuals with autism but also be tantamount to neglect. Without proper and continuous supervision, some of these individuals are at risk from self-injury, pica, or darting. Property and other people might also be at risk. However, the ongoing provision of support can reduce the frequency of these behaviors, limit their effects, and ensure continued employment.

Individuals with autism who do not have severe behavior problems might still require high levels of supervision due to the severity of their

communication and learning problems, in order to maintain employment.

Job/Worker Matches

Although autism does not preclude employment, the characteristics of autism can indeed be incompatible with certain types of employment. Failure to find a suitable job match can lead to job failure. Job development remains a primary concern among new providers of supported employment services. Because the job match can be critical to success (Lattimore, Parsons, & Reid, 2002; McDonnell, Nofs, & Hardman, 1989; Smith et al., 1995), providers do well to concern themselves with this issue.

A primary consideration in job development for people with autism is the interaction of the disability with the demands of the job. Characteristics that might appear to be job threatening could be advantageous in a suitable setting.

Characteristics that can be associated with autism and that can be advantageous in job matching include well-developed visual motor skills, fine motor dexterity, nonverbal reasoning skills, and attention to detail. Several social and behavioral characteristics that might appear to be problematic can also be advantageous. Dependence on routines and difficulty with change can be assets in jobs that have well-established routines. Perseveration on minute details can be advantageous in jobs that require attention to small details. Even the social withdrawal that can be associated with autism can be an advantage to an employer. This would be one employee for whom "social loafing" on the job would not be a problem.

The job match must also take into account behavioral or social deficits that might in fact prove job threatening in certain settings. In those cases, certain types of jobs might be best avoided. For example, individuals who have problems with yelling or who have a loud voice volume should not seek employment in the reading rooms of the public library. Persons with a history of smashing glass should avoid the china shop. However, the former individual could be successful in an industrial site which has a high level of background noise, and the latter individual might be successful at a recycling center.

Good job matches can be found by canvassing the local labor market and seeking job openings that are consistent with the worker's strengths and deficits. An alternative approach is to assist companies in creating jobs that can be handled well by the worker, and which meet specific needs of the employer (Moon, Inge, Wehman, Brooke, & Barcus, 1990). There are incentives for companies to hire people with disabilities, such as tax credits, business recognition, and human service awards (Smith et al., 1995). These job development procedures have served to successfully place individuals with severe autism in employment settings.

Establishing and Maintaining a Worksite

Job support for people with autism, as for other individuals with severe handicaps, extends beyond simply placing the worker in a job. Job support also consists of job orientation and assessment of training needs, on-the-job training of the worker, and stabilization of performance (Moon, Inge, Wehman, Brooke, & Barcus, 1990; Smith et al., 1995). For many workers with autism, intensive, ongoing support in the form of close supervision and implementation of behavior management plans are needed to ensure job success (McClanahan, MacDuff, & Krantz, 2002).

Job orientation and assessment of training needs typically begin prior to the worker starting employment. Support staff determine the worker's job duties. Staff then must learn those duties, determine the routine of the work place, identify supports within the worksite, design instructional strategies, and become familiar with the role of the worker within both the social and the vocational context of the worksite (Moon et al., 1990; Smith et al., 1994).

The precise identification of job duties and routines is especially critical for workers with autism. If a routine is to be varied, it is best to teach variation as part of the routine. Otherwise, if the worker adapts to one routine, he or she may have difficulty in changing to another. Resistance to change can be a characteristic of autism, and this characteristic needs to be taken into account when teaching the worker the new job.

This initial analysis has another critical dimension for workers with autism. Because the worker with autism might have social or behavioral challenges that could have drastic consequences for employment, this initial assessment must include the potential interaction between behavioral challenges and the work environment.

The initial assessment can lead to adaptations of the setting that might be helpful in promoting success at the job despite the presence of challenging behaviors. Individuals with darting behavior may need to be situated away from exits. Workers with loud vocalizations may need to work away from areas with customers. Workers with problems with pica might need to have the area cleaned thoroughly several times per day by the support staff. Workers with aggression or self-injury might need to work some distance from co-workers.

Instructional Procedures

Many workers with autism require specialized assistance to learn job tasks and routine. Workers with autism may have special learning styles to which the untrained employer or co-worker might have difficulty adapting. Experts have demonstrated effective instructional strategies for teaching very

complex technical and vocational skills to people with severe handicaps (Bellamy, Horner, & Inman, 1979; Bellamy, Peterson, & Close, 1975; Wehman & McLaughlin, 1980). Similarly, formal training has improved social skills in persons with autism (Kransny et al., 2003).

The importance of designing and using employment training for individuals with disabilities has previously been identified (Bellamy et al., 1979). A precise task analysis and instructional plan can be very helpful for workers with autism. Hughes and Scott (1997) designed a multistep program for teaching workers with disabilities self-management skills on the job. Once a task is learned, changing the manner in which the task is to be done can present behavioral challenges for workers with autism who become dependent on certain routine ways of performing the task.

Relationships With Co-Workers

Helping the worker with autism develop good relationships with employers and co-workers can be critical. This is especially important for workers with behavioral challenges. At times, the behavior problems that might be associated with autism do occur at work, including aggression, self-injury, screaming, and property destruction. If an individual without autism displays these behaviors, getting fired would be the likely consequence. Maintaining good relationships with employers can be critical and job-saving should behavior problems occur on the job. Studies have shown that co-workers and employers have a favorable view of workers with disabilities (Belcher & Smith, 1994).

Behavior Management

Workers with autism may lose their jobs due to problems in productivity or accuracy. However, more overriding concerns are the significant social skills deficits and behavior problems that can accompany the disorder. Burt, Fuller, and Lewis (1991) reviewed reasons for job loss among workers with mental retardation and cited personal–social problems such as bizarre and aggressive behavior, a factor in failure to retain jobs. Careful implementation of behavior management plans, which include specific training in necessary conversational and social skills, can help workers with autism maintain their jobs despite histories of serious social skills deficits.

Behavior management plans can help the worker with autism meet the social demands of the worksite and can minimize the likelihood that behavioral challenges will threaten employment. Behavioral assessment can be done at the worksite (Moon et al., 1990). Necessary social skills can be targeted and trained. Behavior plans can be developed which can prevent problems from occurring, and which provide for efficient, unobtrusive management

of problems once they do occur. A screaming fit, property destruction, or even aggression or self-injury need not signal the end of employment.

Behavior problems might occur after some time on the job. A functional assessment can be done on site to determine the function of the problem behavior (Smith et al., 1995). The behavior change process at work is similar to that used in the home setting. Behavior management plans might be necessary which alter or mitigate setting events or antecedents, teach alternate behaviors, provide motivation to cooperate at work, and provide the structure needed in order to succeed at the job. Behavior management has been successfully used with adults with autism at work to manage aggression, self-injury, property destruction, and pica (Smith, 1986a, 1987; Smith & Coleman, 1986).

On-the-job instruction in social skills training can be helpful for workers with autism. Workers might need very specific social skills, such as asking for assistance, offering assistance, greeting co-workers and customers, and answering questions of co-workers and customers. Social skills can be taught in short, structured training sessions directly in job settings. Park and Gaylord-Ross (1989) used a problem-solving approach to social skills training at work for three workers with mental retardation with some success. A standard social skills training package was used successfully to improve specific social skills of adults with autism in integrated job settings (Smith & Coleman).

Support Services

Support services can be critical for work adjustment for workers with autism. These services do not differ substantially from those used to support these individuals in their home environments. Behavior support, and support from specialists in occupational therapy and speech and language therapy, can be instrumental in achieving success.

As with residential support services, to be most effective, these services need to be integrated within the job setting, and possibly provided through the job coach or another support person. The actual implementation of the specialist's recommendations can be done directly in the job setting under several models, including direct therapy by the specialist, or through the job supporter (such as the job coach) with supervision or consultation from the specialist (Dunn, 1991).

CURRENT STATUS, OBSTACLES, AND FUTURE DIRECTIONS

Individuals with autism are best served vocationally in supported employment with an *individual placement model.* The individual placement model

allows for individualized job match and job adaptation procedures that take into account the potentially devastating effects of any behavior problems associated with the autism. Additionally, full integration with full exposure to nondisabled co-workers and limited exposure to other individuals with behavioral or learning disabilities maximizes the benefits of learning through modeling. And, conversely, it minimizes the drawbacks of learning from the misbehavior of others with social or behavioral deficits.

Nationwide, greater numbers of individuals with autism are being exposed to supported employment. People with autism have achieved and maintained employment despite severe mental retardation and serious problems with destructive behavior, and have earned meaningful wages (Smith et al., 1994) through supported employment services.

Legislation, such as the Americans with Disabilities Act and the Rehabilitation Act Amendment, has furthered successful employment of thousands of individuals previously viewed as unemployable. States have implemented projects that have realized impressive success in developing local supported employment programs and including individuals with severe disabilities. Supported employment sites for individuals with autism have been established in all 50 states under the auspices of federal grants supporting model program replication.

The development of jobs in nontraditional areas, which are well suited to the needs of people with autism, have allowed these individuals to achieve employment. The provision of sufficient support, including the implementation of behavior management plans tailored to the needs of the employer and to the needs of the worker, has enabled these workers with autism to maintain employment. Meeting these individual needs has been shown to be the most effective characteristic of supported employment programs.

In 1989, Wehman et al. referred to the supported employment program as a promise deferred. In recent years, thanks to legislative gains and the program's successful expansion, the promise is being fulfilled. However, several obstacles to integrated job opportunities still exist. People with severe disabilities are underrepresented, funding is a continual issue, and failure to provide adequate support for sufficiently long periods of time remains a problem (Wehman & Targett, 2002).

Rusch, Chadsey-Rusch, and Johnson (1991) noted that failure to provide sufficient support is a historical problem. These authors suggested that individuals with borderline to mild retardation may now be receiving too much support. However, for workers with severe autism, no verbal language, severe mental retardation, and a history of self-injury, aggression, or property destruction, providing sufficient support remains the challenge; and for many, the obstacle.

Even so-called high-functioning individuals with autism can be vulnerable to this obstacle. Sometimes, the support needs are not as obvious, because the behavioral and communication challenges are more sporadic and less

noticeable. However, when they do occur, they can be job threatening in the short term, and lead to a sporadic history of job success over the long term.

Failure to provide sufficiently effective behavior management support is also an obstacle to successful community integration for this population. Individuals with challenging behaviors have been maintained in supported employment for up to 18 years with the support of job coaches who were intensively trained in behavior management. However, an underestimation of the effectiveness of behavior management with severe behavior problems has contributed to many professionals and service providers continuing to view this population as unemployable.

Difficulties with maintaining a stable, competent staff of job coaches is an ongoing obstacle to maximizing the employability of workers with autism. Job coaches are often entry-level positions with little or no previous experience in autism and supported employment. Although the support agency can provide training to job coaches, follow-through on the part of job coaches can be a challenge. These people, by definition, are working at dispersed sites throughout the community and as such are not under the full supervision of their own supervisors. Their own work habits, or failure to fully implement behavior management plans, can cost the worker with autism his or her job. Additionally, turnover can be a problem, so that the worker with autism and the employer might be subject to frequent turnover of job coaches.

Despite a myriad of obstacles, full integration for people with autism, both at work and at home, has been realized and is currently a reality for a small segment of this population. Allocation of expertise, manpower, and funds needs to be directed toward the application and practice of full community integration, so that many can benefit from the experience of the few. Training, replication, and dissemination activities should be an overriding priority if full integration is to become a reality.

Mr. Markham, the individual described at the beginning of this chapter, has a history of severe behavior problems. He has severe autism and is nonverbal. He has difficulty with pica as well as with severe self-injury in the form of intensive head-banging. Nonetheless, he has maintained competitive, integrated living and employment for 10 years with the help of specialized support. The procedures to support and help individuals like Mr. Markham achieve successful integration have been established, and Mr. Markham has benefited. His peers with autism continue to wait to benefit as well.

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Chapter 14

Treatment Approaches for Autism: Evaluating Options and Making Informed Choices

Raymond G. Romanczyk
Jennifer M. Gillis
Institute for Child Development
State University of New York at Binghamton

THE IMPORTANCE OF INFORMED CHOICE

The premise of this chapter is that consumer-informed choice is a critical aspect of service delivery for children with autism spectrum disorders (ASD). Typically, children cannot make informed choices and must rely on the good judgment of parents, caregivers, and professionals. In most service delivery systems, especially early intervention, great weight is placed on parental preference. This does not mean each family receives exactly the type, proportion, and intensity of service desired, but it does mean that parental preference is a significant factor that is usually considered and discussed.

The unintended reciprocal impact of parental rights is that great pressure and responsibility fall on the parent to choose not only specific goals but also specific intervention methodologies. But how to go about the process of choosing is not universally addressed in a standardized systematic way. Thus, this critical aspect of goal and methodology selection is often accomplished in an information-deficient environment, or in an environment where selective information is presented.

A vast amount of information is available to parents from a variety of sources: professional books and journals, best practice publications, books written for the lay public, conferences, individual professionals, support groups, advocacy groups, and the ever-growing Internet sites. The difficulty,

of course, is that not all information is equal in terms of objectivity, accuracy, credibility, and completeness. With the current ease of book publication and Internet publication, the fact that a book has been published is insufficient as a criterion for credibility. Therefore, making an informed choice by obtaining information from a credible or expert source is highly desirable. But it is difficult to identify with ease which sources of information actually provide information accurate enough for a parent to make an informed choice. This is especially true for identifying "experts," because popularity and charisma may have greater influence than validated accuracy of the information presented.

DIMENSIONS OF DECISION MAKING

Parents (and professionals) adopt a number of strategies to address the dilemma of goal selection and intervention methodology choice. These strategies may or may not be preceded by extensive self-education from sources such as those mentioned previously. We categorize the typical strategies and present them in colloquial fashion:

- "They know what's best." Place trust in a service provider to choose (pediatrician, school district, case manager, etc.). Trust may be based on reputation, personal likable qualities, willingness to spend time with parents, promises of effectiveness, minimizing child's deficits, and offering good prognosis.
- "Hedge your bets." Do a little bit of everything in the belief that it can't hurt, and that a diverse "package" will be of help even if some of the individual treatment approaches are not really effective. Also known as the "everything but the kitchen sink" approach, this approach assumes that all components are compatible with one another that the balance and sequence between approaches are not important and that the amount (or dosage) of intervention approaches is not critical.
- "Fanatical focus." Pursue a single course with overwhelming intensity and focus that goes beyond the typical recommendations. The essence of this strategy comes from two sources: the false belief that if a specific "dosage" is good, then increasing it is better; and the emotional comfort that comes from putting all of one's energy into a loved one's care. Such extreme focus is often based on a lack of understanding of the empirical literature and on a lack of appropriate child-centered assessment and evaluation information. This approach has the additional risk of placing great strain and emotional drain on the family.
- "Hope for the best." Forgo formal treatment and participate in typical activities that are available. Parents may be influenced by family

members who don't "trust" professionals, may have examples of family members, or knowledge of other families, where someone was slow to develop and ultimately "turned out fine." This approach can also stem from denial of the problem due to emotional conflict and fear and can be associated with anger directed at a professional who is responsible for making the initial diagnosis.

- "Cure du Jour." Pursue each new treatment as it appears and drop the current program. This approach stems from the "new is better" philosophy and often reflects being overly influenced by marketing, "breakthrough" announcements in the media, and the simple repetition of history. Approaches found to be inadequate tend to come back in cycles as the information about the approach is forgotten or the approach is now described in different terms.
- "A friend told me." Do what seemed to work for the child of someone you know or have read about. As has been made clear in preceding chapters, autism spectrum disorders encompass a heterogeneity of specific child characteristics and expression of severity. This approach is as ill advised as sharing medication for an illness you have with a friend who "has the same problem."
- "Guru selection." Following and believing in a single, specific "expert"—similar to "fanatical focus," in that information is used selectively and the decision is strongly emotionally based because the approach is packaged in the context of the "expert" having made "breakthroughs"—is outside the "establishment"; requires "loyalty" by not challenging information presented; is disparaging of other professionals, often at a personal level; and uses seemingly impressive case studies to prove the approach works. Guru promotion is often accompanied by statements that the person is concerned with helping people and not in doing research. Effects are claimed to be "obvious."

None of these strategies is surprising. Selection of intervention methodology is very complex and each person comes to the process with different information and life experiences. When one factors in the emotional aspects of selection while under pressure and often simultaneously coming to grips with a recent diagnosis, the aforementioned strategies are all the more understandable.

We attempt to assist in the process of goal section and intervention methodology selection by providing information about treatment options, organized in a number of different ways, to address the many issues that families face. A separate issue from intervention methodology selection that we cannot cover in detail is service provider selection. This is also complex, as all treatments are dependent on the skill and training of the service provider. Unfortunately, there is little useful regulation of service providers

and consumers must become aware of the differences between meaningful professional credentials and simple self-promotion.

EVALUATING EFFICACY OF TREATMENT APPROACHES—LARGE-SCALE CONTEXT

A useful starting point is to examine the factors that enter into informed decision making.

Some of these are:

- The decision is not coerced.
- Specific treatment can be declined without penalty or retribution.
- Information is made available which allows one to be informed.
- The information is objective; that is, it is derived through scientific means, not through opinion.
- The information is not censored, restricted, or limited.
- If the information is provided by a service provider, be aware that it may be self-serving.
- If the information is provided by a funding agency, be aware that it may be self-serving.
- The decision to use a treatment approach is revocable.

These are some of the issues that must be addressed to allow informed decision making, and they are often accomplished through a group process, such as with a school district committee on special education or a county department of health, to assist in a reasoned outcome. However, central to this process is that the information being reviewed in order to make a choice is accurate. How to evaluate such information is the focus of this chapter.

WHAT DOES EVIDENCE-BASED TREATMENT MEAN?

There is wide variation among people in what the words *research*, *effective*, and *proved* mean. Most people are not scientists; thus, precise meaning gets lost and often results in confusion. The Internet publishes *proven* treatments that in fact are not proven to be effective and, worse, that have been shown to be detrimental. Sadly, no objective, ongoing clearing house, using a validated evaluation methodology, currently exists. Therefore, the individual must look to various sources of evaluation, and rely on the process of scientific study that seeks to find objective answers to complex questions. Fortunately, we do have some excellent sources of research evaluation.

Research spans a continuum of questioning and testing, from naturalistic observation, anecdotal reports, case studies, controlled single-subject

studies, clinical trials, and finally methodologically controlled outcome studies. The ultimate criterion for information concerning treatment methodology selection is the controlled research study.

What are the critical components of good research for the purpose of deciding whether a specific treatment is effective? This is a critical question for those who are influenced by objective evaluation and for those who prefer to make decisions concerning their child's well-being based on objective information rather than on emotional reaction or unsupported claims of successful procedures.

The first component of good research is the objective measurement of behavior. This component is the lynchpin of a worthwhile study. Unless researchers can reliably and accurately measure the behaviors and processes of interest, then results may simply be an artifact of improper measurement. Most measurement systems have technical pros and cons, as well as having practical cost-effective parameters. There is a large body of literature within the field of science in general, and psychology in specific, that indicates human observers are prone to a number of very specific errors in conducting observations. A classic example of unintended influences on perception is that of the great astronomer Percival Lowell. He mistakenly identified over 150 canals on Mars. Given the limitations of telescopes at the time, the image he saw was fuzzy and ambiguous, although his drawings were very sharp and detailed. He was not making up what he saw in the sense of intentionally falsifying his results; rather he was trying to be an objective observer. We are all subject to influences and biases that limit our objectivity. One credible reason for this difficulty in objective measurement is that one of our strengths, with respect to information processing, is the ability to detect patterns. However, as with all systems, our ability to detect patterns is not perfect. We are able to perceive specific patterns where, in fact, none exists. We can be differentially influenced by information, context, and experience that have emotional as well as informational content. Another example is the classic taste test. By providing several different beverages and asking for a preference, knowledge of which beverage is which can be a strong influence on selection. This is why *blind* testing is useful in order to separate out the role of expectation versus actual perception of taste sensation.

Often in clinical and educational service delivery we violate this basic principle so that the individuals performing assessment, delivering services, and evaluating outcome are one and the same. It is important to stress that the influences that limit our ability to make objective observations are not primarily based on such factors as sophistication, education, falsification, intentional bias, or deception. Rather, they are based on information-processing limitations shared by all humans. We can demonstrate quite clearly and consistently that there are factors that can influence a person's perceptions while still having the person completely convinced that they are being

objective and accurate. Thus, we can observe instances in which even though a person firmly and sincerely holds the opinion that a specific change of behavior has occurred, in fact, the individual is quite mistaken when this judgment is compared to an objective standard (Jacobson, Mulick, & Schwartz, 1995). By understanding these processes, one can guard against potentially inaccurate observations, and conclusions can be avoided.

Thus, the *sine qua non* of good research is that objective measures are taken of behavior and that these measures must meet the boundary conditions of being operationally defined, reliable, and valid. Operational definitions simply translate the normal colloquial reference that we give to certain behaviors into more objectively defined observational terms. A good example would be attempting to assess a child who is *moody*. This is a term that most individuals would recognize and believe that they have an understanding of its meaning. Another colloquial term commonly used and believed to be understood is *anxiety*. Difficulty arises with respect to precision in the application of such terms to an individual. For example, with anxiety, one could view it as a construct, the summation of a number of different factors that are assumed to be coherent. We can divide the imprecise construct of anxiety into a number of components:

- *Cognition.* What is the individual thinking and feeling? Such information is beyond the realm of current measurement technology. It is by definition a private event; therefore, we cannot have access to it.
- *Self-report.* The information the individual provides to describe the internal cognition and feeling. It is important to note that cognition and self-report are not equivalent. It should not be presumed that self-report is necessarily an accurate reflection of private events.
- *Overt behavior.* The individual's observable behavior patterns are assumed to be reflective of anxiety. This could include observing someone perspiring, where the ambient temperature would not normally elicit such a response; fidgeting; pacing; and avoiding eye contact.
- *Performance.* The quality, quantity, and rate of task-oriented behavior. Simple examples include how well one does on tests, putting toys in a toy box, writing a letter, and reciting the alphabet. Judgment is not of how the product is produced, but rather of the quantity and quality of the product.
- *Physiological.* Measures of bodily processes that do not have an immediate or apparent visual component. These would include heart rate, blood pressure, respiration, galvanic skin conductance response, and EEG. Because this type of information is often not easily available to the observer, greater reliance is placed on the other three observable categories: that of self-report, behavior, and performance.

Thus, although anxiety is a useful term for the purpose of communication concerning a problem the individual is experiencing, from a research perspective it would be broken down into the aforementioned categories in order to allow individualized assessment for a given person as to how specifically anxiety is manifested in the individual. This illustrates why using questionnaires, checklists, and surveys about an individual's behavior is usually the least accurate way of collecting data, although it is usually the least expensive and, therefore, widely used. The most useful measurement is of direct observation of behavior by observers who are "blind" to all aspects of the research and who do not know which subjects are and are not receiving treatment.

Reliability of observation refers to the degree to which various specific behavioral observations conducted by different observers are in agreement. This is typically done by having two independent observers perform observations and then comparing very precisely the degree to which they agree and disagree on the specific temporal pattern of the behaviors observed. To the degree that the individuals have *not* been given specific expectations such as "medication started yesterday," "we are seeing problems with rising anxiety," or "it's clear he's anxious and we need to document that," this type of operationalized, unbiased, reliable observation serves as the basis for evaluating treatment effectiveness. Sadly, it is typically lacking in most research reports, permitting exaggerated claims to be made by service providers.

OBJECTIVE REVIEWS OF TREATMENT EFFECTIVENESS

Where do families look for answers to questions about treatment effectiveness? The typical answer is through service providers, the Internet, or through others who have faced similar situations. But as discussed previously, this is not a sound approach because it limits your information solely to sources that probably are not applying rigorous, objective evaluation to treatment claims.

Fortunately, there is an accepted methodology for evaluating treatments (Holland et al., in press). This methodology was formalized by the U.S. Agency for Health Care Policy and Research (AHCPR) in the process of developing 19 evidence-based clinical practice guidelines, which were released from 1992 to 1996. This agency, now named the U.S. Agency for Healthcare Research and Quality (AHRQ), is part of the United States Public Health Service and is the primary federal agency involved with health services research (Holland, 1995).

The AHCPR clinical practice guideline methodology uses principles for developing high-quality practice guidelines recommended by the U.S. Institute of Medicine. This AHCPR methodology is considered to be the standard

TABLE 14.1
A Short Listing of the Array of Treatments for Autism

Acupuncture	Accupressure	Animal-Assisted Therapy
Antiyeast Therapy	Applied Behavior Analysis	Art Therapy
Auditory Integration Training	Augmentative and Alternative Communication	Chelation
Chiropractic	Craniosacral Osteopathy	Dance–Movement Therapy
Deep Pressure Therapy	Discrete Trial Training	Dolphin Therapy
Elimination Diets	Facilitated Communication	Fluency Training
Gentle Teaching	Greenspan's Floor Time	Holding Therapy
Homeopathic	Hyperbaric Oxygen Therapy	LEAP*
Linwood Method	Massage	Miller Method
Music Therapy	Naturopathy	Neuro–Bio Feedback
Occupational Therapy	Option Therapy (Son-Rise)	Orthomolecular Medicine
Patterning	PECS†	Pharmacological
Physical Therapy	Pivotal Response Training	Play Therapy
Precision Teaching	Psychopharmacology	Reflexology
Scotopic Sensitivity Training (Irlen Lenses)	Scripting	Secretin
Sensory Integration Training	Social Stories	TEACCH
Touch Therapy	Verbal Behavior Training	Vision Therapy
Vitamin Therapy		

* LEAP: Learning Experiences: An Alternative Program
† PECS: Picture Exchange Communication System

for developing evidence-based clinical practice guidelines (Eddy, 1994; Holland, 1995; Schriger, 1995; Woolf, 1991, 1994).

This methodology was recently applied to autism spectrum disorders. The New York State Department of Health (NYSDOH) Early Intervention Program selected the AHCPR methodology to develop a series of evidence-based clinical practice guidelines focused on identification, assessment, and intervention for young children with developmental problems. One goal of the process was to provide families and service providers with recommendations based on scientific evidence. A second goal was to stimulate further research by documenting the current state of scientific knowledge.

Over 8,000 research reports were reviewed and evaluated using objective criteria for sound research methodology. This process resulted in a group of research studies that were used for the specific recommendations, which cover many of the treatments listed in Table 14.1. These guidelines are available in their entirety from NYSDOH.

Beyond the rigorous methodology and cross-checks used in the guidelines, another critical element of good scientific methodology is replicability. That is, it is critical that someone, other than the original researcher, be able to follow the published procedures and obtain the same results. In other words, it is necessary to be able to reproduce results by other independent researchers. The same applies to the process of establishing guidelines. If

the process is objective and well specified, then another group should be able to duplicate the findings, because they are not based on mere opinion, but rather on an analytical process that has specific rules.

It is noteworthy that several other objective treatment reviews have occurred recently. One is "Educating Children with Autism," authored by the Committee on Educational Interventions for Children with Autism, Division of Behavioral and Social Sciences and Education, of the National Research Council, published by the National Academies Press. The committee was composed of some of the most prominent figures in autism research in the nation. The report was commissioned by the U.S. Department of Education's Office of Special Education Programs to "consider the state of the scientific evidence of the effects and features of early educational intervention on young children with autism spectrum disorders" (p. 2). The committee takes a similar approach to the NYSDOH process and cites it as a reference. They state that: "To achieve a systematic and rigorous assessment of research studies, the committee established guidelines for evaluating areas of strength, limitations, and the overall quality of the research . . ." (p. 14). This report does not offer specific treatment recommendations as does the NYSDOH guidelines, but does provide evaluative statements, such as in the context of sensory integration therapy that: "These interventions have also not yet been supported by empirical studies" (p. 99). Another example is the statement that "By far, the bulk of autistic spectrum disorders intervention research has been conducted from the perspective of applied behavior analysis" (p. 148).

Another important example comes from the recent Report of the Surgeon General (1999) concerning mental health in the United States. It is quite specific. In the section on children, specific reference to autism is made. The report states:

> "Because autism is a severe, chronic developmental disorder, which results in significant lifelong disability, the goal of treatment is to promote the child's social and language development and minimize behaviors that interfere with the child's functioning and learning. Intensive, sustained special education programs and behavior therapy early in life can increase the ability of the child with autism to acquire language and ability to learn. Special education programs in highly structured environments appear to help the child acquire self-care, social, and job skills. Only in the past decade have studies shown positive outcomes for very young children with autism. Given the severity of the impairment, high intensity of service needs, and costs (both human and financial), there has been an ongoing search for effective treatment.
>
> Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior." (http://www.surgeongeneral.gov/library/mentalhealth/chapter3/sec6.html#autism)

Given the basic and applied research (not simple case reports or anecdotal reports) and authoritative reviews, such as that previously cited; the evidence is very strong that applied behavior analysis is a well-validated and effective treatment approach. The many varied other treatment approaches as illustrated in Table 14.1 lack sufficient research support. In most cases the lack is an absence of sound research, whereas for others, such as Facilitated Communication, there is a large number of well-controlled research studies that demonstrate its ineffectiveness.

EVALUATING EFFICACY OF TREATMENT APPROACHES—INDIVIDUAL CHILD CONTEXT

Goal Planning and Selection

There are several common elements considered by some to be associated with effective treatment. These include assessment (both prior to goal selection and throughout intervention), specific curriculum content, highly supportive teaching environment, clearly prescribed generalization strategies, predictable routines, functional approach to problem behaviors, well-planned transition, and ongoing family involvement (Dawson & Osterling, 1997). Chapters 8 and 9 discuss the importance of assessment and effective teaching strategies for children with autism. Thus, these topics are not covered here. This section of the book focuses on an individualized approach to goal planning and selection, how family involvement influences goal selection, the difficulty of setting realistic goals, and evaluating treatment program progress.

Family Context

A family's primary role for any child is to love, nurture, and protect. Each family is different and presents with different needs, challenges, advantages, disadvantages, resources, and values. Goal selection must take place within the context of the family environment and family values. For example, one family may consider toilet training essential before a child turns 4 years old, whereas another family may prioritize self-dressing over toilet training. Additionally, many parents desire that their child participate in age-appropriate and community-related activities. In order for this to take place, the resources in the community must be identified in order to provide support for the family and child to pursue such goals, and a child must be taught the prerequisite skills in order to participate in specific activities.

The impact of a treatment program and the types of goals selected for a family are critical considerations. What type of financial hardship will a

particular treatment program place on a family? Families have a constant struggle with the question of "who's footing the bill?" What does a treatment program require of the family? Will it change family member roles and interaction? If so, to what degree? Will it affect family members differentially? These questions must be addressed when selecting goals in the context of a treatment program(s) and when devising a goal plan for a child with ASD.

Assessment

When planning for goal selection for children with autism, assessment is a central component. Prior to goal selection, both psychometric and behavior analysis and functional assessment procedures must be conducted. Standardized psychometric assessment is widely used for children of all ages. The purpose of standardized assessment is to compare an individual's performance on tests of specific abilities (i.e., acquired knowledge, reasoning, and novel problem solving) to that of similar individuals (age, grade placement, gender) who took the same tests under similar conditions. The scores derived from administration of these measures are very useful in goal selection. Standardized assessment is also critical for diagnosis and placement decisions, evaluating outcomes, and measuring the effectiveness of educational programs.

In the context of goal planning, standardized assessment provides information about children with autism in relation to typical, same-age peers. Using standardized assessment may provide a marker of progress to date and is helpful in the selection of developmentally age-appropriate goals. Standardized assessment also assists with goal selection in that it identifies strengths and weaknesses in different skill areas for children with autism. Because standardized assessments are not a routine part of a child's activities, they provide an opportunity to observe and evaluate a child's behavior in a novel situation.

As important as standardized assessment is for goal selection and the evaluation of child progress, there are many difficulties with conducting standardized assessments with children with ASD. Standardized assessments are important in that they provide a standard of normative behavior against which to compare the performance of children with autism and Pervasive developmental disorder (PDD). However, to date, there is no consensus as to what comprises a standard assessment battery for evaluating young children with ASD. Thus, it is up to the evaluator or evaluating agency to decide which assessments to use. This may be problematic when attempting to evaluate child progress, because different assessments may be employed and may not be directly comparable. Due to the fact that there is no agreed-upon assessment(s) for measuring progress for a child with autism, many

evaluators will use nonstandardized tests and subjective opinions. This is to be avoided.

Another consideration with standardized assessment is that children with autism and PDD typically perform poorly during testing situations for several reasons. Some of these include:

- Poor attention
- Behavioral excesses that may interfere with valid measurement of child ability
- Poor test-taking skills (i.e., limited awareness of expectations during assessment sessions)
- Poor language comprehension (i.e., verbal and gestural language)
- Limited ability to generalize skills across settings, people, and task materials (i.e., students may have skills that they do not perform in novel settings with unfamiliar adults)
- Disruption of daily routines for assessments (i.e., given that children with autism may strive for routine and sameness, they may be in distress and test results may not reflect their abilities under more typical conditions)
- Impaired social skills (i.e., meeting and working with new people are not perceived as pleasant events and adult attention may not be rewarding)

Behavior analysis and functional assessment are important parts of the overall assessment process for goal planning for children with ASD, as these types of assessments do not evaluate but rather place the child's development in perspective. Behavioral assessment involves analysis of behavior. Behavior analysis involves the identification of variables that affect learning, behavior, and performance. In terms of goal planning and selection, behavioral analysis and functional assessment allow for assessment of teaching and response modality in addition to an assessment of motivation (reinforcer assessment). Behavior analysis and functional assessment can determine the extent to which the difficulty level of a task or certain aspects of a task affect performance behavior. Identification of specific environmental variables' effect on performance behavior can also be derived from behavior analysis and functional assessment therein influencing goal selection.

Because goal selection is a complex process, comprehensive assessments with children with autism should be comprised of multiple measures with multiple sources of information to construct an individualized goal plan that is appropriate for a specific child. In summary, assessments should include some traditional testing, as well as observational and behavioral checklists completed at the time of assessment and by individuals who know the child well (e.g., parents, teachers, and other caregivers). What is most important is that test data be interpreted cautiously, with consideration of impediments

to optimal performance, because these data will provide information that will heavily influence the goal selection and goal plan for a child with autism.

How Does Assessment Contribute to Goal Selection and Planning?

Prior to the start of goal selection, a thorough review of assessment data should be conducted. Global test scores from standardized assessments provide indications of general areas of strengths and weaknesses. In addition, qualitative aspects of child behavior during assessment are important considerations for goal selection. For example, the child's ability to follow directions and to interact with an adult in a structured setting, the amount of frustration observed when the child does not acknowledge the task or the answer, and the amount of distractibility throughout the assessment session can all affect performance.

Given information gathered from both standardized and behavioral assessments, it is at this point that the difficulty of balancing family priorities for goal selection and the information gathered from assessments must be accomplished in order to develop a goal plan that contains realistic (i.e., achievable) goals.

WHAT ARE "REALISTIC" GOALS?

Setting realistic (achievable) goals is one of the biggest challenges in the goal-planning process for children with autism. Realistic goals are those that take into account a child's current level of functioning, learning rate, strengths and weaknesses, chronological age-appropriateness of goals, and the impact on family. Unrealistic goals may be selected when thorough assessments are not conducted and the complexity of a specific goal is not fully understood by all concerned. This begs the broader question: What is achievable? How soon? To what degree? For instance, will a child achieve independent use of augmentative communication? At one level, such questions are unanswerable for a given child with certainty prior to intervention. This is where we must rely on assessment information, parental and professional experience, and objective research to formulate a set of goals that are based on a process of selection that is systematic, and not simply based on a desire for achievement.

We break the goal plan process into three primary parts: short-term goals, intermediate goals, and long-term goals, allowing for consideration of what goals are achievable in the near and distant future. It should be noted that a goal plan is not a rigid or set-in-concrete plan but rather a process. As

short-term goals begin to be acquired, and as the child's progress is closely monitored, this provides valuable information and thus goals selected as part of the intermediate and long-term aspects of a goal plan may be modified or deleted, or new goals may be added. Child progress should be monitored on an ongoing basis because goals that once were deemed to be realistic can become unrealistic. Goal selection is a dynamic, feedback-driven process.

Goal Selection: Pros and Cons of a Team Approach

Most teams include the parents, educational experts (which may include a wide range of professions from special educators to speech pathologists to occupational therapists), and, if appropriate, the child. The purpose of a team approach in goal planning and selection is to bring to the table different areas of expertise to help guide goal selection that is appropriate, functional, both vertically and horizontally integrated, and community referenced. In consideration of the multiple areas of development (e.g., cognition, communication, emotional, behavioral, and motor) that need to be addressed in the process of goal selection, having experts in these areas is common practice.

There are also many difficulties with a team approach. The primary responsibilities of a team are to help parents develop an Individualized Family Service Plan (IFSP) or Individualize Education Program (IEP) that is most appropriate for their child (chap. 9). Members of the team can greatly influence treatment choice. The opinions of the different professionals in particular may impact a parent's decision about goal appropriateness. Balancing areas of focus in goal selection can be difficult if the team members are determined to include their own treatment choice in an IEP or IFSP rather than focusing on the individual child's needs.

The following is a sample of questions that should be a part of the discussion at a team meeting when goal selection and planning are taking place:

- What are the prerequisites?
  This includes the repertoire of skills that a child needs to have already mastered in order to be able to learn the goals selected in the IFSP or IEP. What skills does the child have and what skills does the child lack? For example, does the child imitate simple actions? Can the child imitate verbal behavior? How long can the child sustain attention to a task or activity?
- What is the time frame in which selected goals will be addressed?
  This question allows the team to collaborate in terms of prioritization of goal selection and estimates on speed of achievement. That is, which goals should be addressed first and why, and what length of

time may be necessary to achieve the goals? Short-term goals should be associated or linked to intermediate goals and long-term goals. There should be a clear connection between the goals within the goal plan. For instance, if a short-term goal is to follow simple directions, then a long-term or intermediate-term goal might be to follow multistep directions in the context of social play in a small group.

- What are the expectations?

  How soon should results be expected? What are roadblocks, if any, foreseen in the future when attempting to teach a particular goal? In setting realistic expectations for a child, expectations of parents and teachers need to be considered.
- What are the acute and chronic resources?

  This question is one that both parents and team members must consider in the development of a goal plan. Resources that are required for short-term and long-term goals should be discussed. Identification of resources does not just include the number of service providers, such as teachers and aides, but also the type of community resources (e.g., after school groups and recreational activities), educational resources, and support resources for parents and siblings, as well as monetary resources to pay for the types of services required in the goal plan. It should not be assumed that all resources are necessarily present or will be forthcoming. This factor can affect goal selection and prioritization.
- What is the schedule of review?

  In other words, how often will progress toward a particular goal be monitored (e.g., weekly, biweekly, and quarterly)? Who will review the progress for particular goals? The schedule of review may be different for each goal or goals within an area. For example, language acquisition goals may be monitored more frequently (e.g., weekly) when a child is just learning to imitate sounds; however, a social skills development goal, such as playing a simple game with peers, may be monitored every 2 weeks. The schedule for review of goals will be determined by the priority of certain goals and the child's learning pattern within different goal areas.
- What is the evaluation method, including criteria?

  In tandem to the schedule for review of goals, is the evaluation of the goals. Determining the manner in which goals will be evaluated to monitor progress is essential for any goal plan. It is important to measure progress for each of the goals that a child is currently working toward. A major part of the measurement and evaluation process involves setting a criterion for each goal. Criteria serve as markers of achievement for goals or subparts of goals. For example, for the goal of matching pictures to objects, the criterion may be set

at the child performing 85% correct responses for two consecutive teaching sessions with each subset of 10 pictures and objects before progressing to the next subset of pictures and objects.

AIMM—ASSESS, INTERVENE, MEASURE, MODIFY

The evaluation of a treatment program's effectiveness for a child is a challenging task. However, it is a crucial task when the desire is to maximize a child's progress. We have developed a model that captures these different elements that we refer to as AIMM (Lockshin, Gillis, & Romanczyk, 2001). AIMM is an acronym for Assess, Intervene, Measure, and Modify. The AIMM model captures the spirit of maximizing child progress. Critical AIMM elements for the determination of treatment efficacy for an individual child are described briefly in the following sections:

Assess

Referring to earlier parts of the chapter, assessment is the first necessary aspect of treatment planning. Assessment provides the groundwork for determining appropriate treatment and goals. Both standardized and behavioral assessments are included in this stage. In addition, functional assessment, if needed and/or an assessment of skill repertoires is essential. Information from this initial part of the model helps to determine what type of treatment program may be beneficial, how often and how much (intensity) of a treatment procedure is warranted, how family context is incorporated into the treatment program, and prerequisite skills needed to achieve goals.

Intervene

At this stage, identification of which treatment program(s) will be used and goal selection take place. Targets for intervention (i.e., which behaviors need changing) are defined and prioritized. Goal selection considers and integrates results from the assessment phase, family priorities, and prioritization for targets for intervention. Effective implementation of goals with respect to a particular child's goal plan is made possible through careful systematic planning.

Measure

How will progress be measured and reported? Questions concerning measurement include how often measurement will take place, which behaviors

or performance will be measured, and who will be monitoring measurement process. Depending on the nature of a specific goal, behavior may be measured in 15-minute intervals, hourly, daily, and weekly. The type of measurement, such as a frequency count, noting if behavior occurred or did not occur in a specified time period, and intensity measure, is another important consideration. Typically, a specific goal will determine the type of behavior that is measured. For instance, a goal set to decrease self-injurious behavior (SIB) might measure the type, intensity, and frequency of the occurrence of SIB. Clearly, measurement is key for evaluating child progress.

Modify

In order to modify a treatment program approach, accurate measurement must occur. This phase assesses which goals are being met as scheduled and whether to add more goals, subtract goals, change the intervention approach, or a combination of these. If some goals are not being met in a timely fashion one must assess why they are not, such as lack of prerequisite skills, inadequate motivation, and instruction that is too infrequent or widely spaced. Behavioral assessment comes into play also in order to address problems that may arise from interfering behavior or maladaptive learning styles, such as prompt dependancy. The AIMM cycle is repeated continuosly and serves as the process that binds goal selection to goal achievement.

CHOOSING A TREATMENT APPROACH

Throughout this chapter many questions were raised to alert both parents and professionals to the complex decision-making process surrounding goal selection, treatment selection, and progress evaluation. There are hundreds of proposed *treatments* for autism and new treatments being proposed constantly. Treatments are heralded with great enthusiasm but quickly fade from the limelight.

Treatments and treatment programs for autism tend to follow a specific life cycle. It is important to understand the life cycle of a treatment in order to understand why there are so many claimed treatments for autism. The life cycle of a specific treatment (treatment X) usually starts with an anecdotal report of the treatment's effectiveness with one or more children with autism. Most anecdotal reports originate with the proponent of a new treatment or from parents who report that it worked for their child. Treatment X then may take several different courses. Treatment X may be spread via word of mouth, media, support groups, and the Internet. These methods of dissemination tend to result in several different outcomes. For instance,

for some period of time treatment X may be accepted by parents and therapists as effective and incorporated into a treatment plan. Another, yet rare outcome is that treatment X will undergo empirical testing to determine its degree of effectiveness. It is not uncommon in the field of autism for treatments that once were thought to be effective to not stand the test of time and to drop into disfavor.

What is troubling about the typical life cycle of treatments for autism is that there may be many approaches in vogue at one time, that there is insufficient time and resources to conduct controlled research to determine effectiveness. Thus, only a few treatments are subjected to empirical study. This leaves hundreds of treatments for autism untested and still "out there" for parents to choose from and decide whether or not to take a chance.

So now the question is, when does a treatment come to the end of its life cycle? The answer to this question is complex and variable. The following example illustrates this point.

Facilitated communication (FC) is a treatment for autism that has undergone several of these aforementioned stages. FC was first introduced in the United States, in 1990, by Biklen (1991). Facilitated communication is a treatment method that involves the physical assistance and emotional support from a facilitator who enables a person with autism to communicate, typically, with a keyboard. Because FC was purported to be an effective and very rapid treatment for autism, the media popularized FC very quickly. Facilitated communication appeared to be an easily learned and expeditious treatment for persons with autism to communicate with others. Facilitated communication was quickly adopted by therapists, families, school systems, and many segments of the autism community. Soon, however, court cases began appearing that described children with autism accusing, via FC, a parent, grandparent, or other person of abuse. The gravity of the accusations caused concern as to the validity of FC. Research on the role of the facilitator in FC and the validity of FC as a treatment method ensued. Methodologically sound empirical studies that included control groups indicated that FC was not an efficacious treatment and that facilitators were, in fact, influencing responses. These results were summarily dismissed by proponents of FC. It was argued that FC relied on the facilitator having a trusting and emotional relationship with the individual with autism. Thus, when testing of the technique occurred, proponents of FC claimed that testing violated the established trust and individuals would choose not to respond or respond incorrectly. These concerns were addressed in continuing research, and the current sum of research evidence is clear: FC is not an effective treatment. However, FC is currently being used in the United States, although it is not always formally labeled as FC. This recycling of a treatment is often seen in autism. Therefore, parents must be cautioned to look beyond a treatment's

name and supposed reasons for effectiveness. The following red flags should be considered when deciding on a treatment choice for a child with autism. Note: The presence of a red flag is not necessarily sufficient to disregard a treatment as a possibility, but rather serves as a caution.

Red Flags

1. Is the founder of the treatment the same person who has conducted the evaluations on the treatment?
2. Has research on the treatment been published in peer-reviewed journals?
3. Is the proposed intervention easy with promises of quick results?
4. Is it a breakthrough that has little history of development and testing?

SO JUST TELL ME—WHAT WORKS?

This chapter has been a long answer to a deceptively simple question: What treatment works? This important question has several answers. First it depends on how *works* is defined. From a research perspective, based on the principles presented in this chapter, it is clear that at this point in time applied behavior analysis would be the treatment of choice. If Table 14.1 were to include only treatment approaches that had empirical evidence for clinically significant effects, it would be a short table. To date, the general behavioral approach often referred to as applied behavior analysis has clear and substantial research support. This statement cannot be made for any other treatment approach.

The determination of whether an intervention *works* includes the subjective influences presented in Table 14.2. The answer is more complex as it is a question of perception. Does the treatment reward personal psychological needs and beliefs? For example, a treatment that is enjoyable, feels good, and elicits positive emotion and activity will usually be interpreted as effective, even though it produces no documented long-term habilitative outcome for the child. Similar to the placebo effect, perceptions are influenced by expectations and context.

Finally, effectiveness must be evaluated from the point of view of the individual child. Stating that a treatment is effective does not mean that it will necessarily work for *each* child to whom it is applied. Rather, it is a probabilistic statement as to positive outcome. It is because of this that we have emphasized the process of assessment, goal selection, and evaluation, exemplified by the AIMM model which transcends any particular treatment approach. This model is used to underscore that information from research should guide decision making, but always in the context of

TABLE 14.2
Comparison of Objective and Personal Evaluations of Factors That Influence Treatment Choice

	Objective Evaluations			*Personal Evaluations*			
Factors to Consider	*Can It Be Quantified?*	*Can It Be Explicit?*	*Is There Credible Information?*	*Gut Feeling Impact*	*Personal Values Impact*	*Emotional Feelings Impact*	*Practical Impact*
Availability	√	√	√	—	—	—	√
Comfort Level With Approach	—	—	—	√	√	√	—
Comprehensiveness of Approach	√	√	√	√	√	√	√
Cost	√	√	√	—	—	—	√
Evidence Based	√	√	√	—	—	—	—
Family Involvement Required	√	√	√	√	√	√	√
Intensity of Approach	√	√	√	√	√	√	√
Perceived Emotionality of Approach	—	—	—	√	√	√	—
Philosophy of Approach	—	√	—	√	√	√	—
Theory of Approach	—	√	√	—	—	—	—

rigorously evaluating effectiveness for the individual child who receives a particular treatment approach.

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