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Jonathan Tarbox
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Handbook of Early Intervention for Autism Spectrum Disorders

Research, Policy, and Practice

Springer

Autism and Child Psychopathology Series

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Preface

Early intervention for children with autism spectrum disorders (ASD) is an increasingly popular and well-researched field of inquiry. However, as both popular attention and scientific activity grow, so too does the spread of misinformation. The purpose of this handbook is to put together in one place the latest in scientific information pertaining to the assessment and treatment of young children with ASD. To that end, the editors are pleased to assemble a world-class collection of scientists who have authored chapters touching on a wide variety of topics relevant to the field.

The first part of this volume, “Diagnosis and Background,” brings together a collection of chapters that lay the foundation for autism treatment. The final editing of this volume coincided with the publishing of the DSM V, which significantly changed the criteria for autism diagnosis. Therefore, many of the chapters in Part 1 dance a delicate balance between being current with the new diagnostic criteria, yet summarizing and analyzing the results of relevant research, nearly all of which was done with respect to the old diagnostic criteria.

Part 2 of this volume, “Intervention,” aims at addressing a relatively comprehensive scope of topics on evidence-based treatment for young children with autism. Hundreds of treatments for autism have been proposed but the vast majority retain little-to-no scientific support. Accordingly, all the intervention chapters in this volume focus strongly on aspects of autism intervention which have been the subject of rigorous scientific research, most of which are founded largely or wholly in applied behavior analysis. Chapter 23 rounds out the collection of intervention topics by directly addressing controversial treatments for which there is little or no evidence. Finally, Chaps. 24, 25, and 29 expand the scope by addressing issues related to family systems, general medical disorders, and multicultural issues, respectively. It is hoped that this volume provides a useful reference in the daily work of researchers and practitioners, as well as a springboard to spur further research into still under-addressed areas of assessment and treatment of children with ASD.

Acknowledgments

The editors would like to thank all of the world-class authors whose contributions made this volume possible. The editors would like to especially thank Brian Belva and Adel Najdowski for their organizational support for the project.

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Part I
Diagnosis and Background

Evolution of Autism: From Kanner to the DSM-V

1

B. Andrew Adler, Noha F. Minshawi and Craig A. Erickson

Keywords
Diagnosis · History

Leo Kanner was a man who possessed the truly rare gift of being able to step back and see the big picture. At the time when his initial case series was published in 1943, the children Kanner described would have been diagnosed with childhood onset schizophrenia. At that time, children with severe psychiatric illness were frequently placed into this single, all-encompassing diagnostic category. However, Kanner recognized several distinguishing characteristics of these children which made them different from those with schizophrenia. He identified the disorder impacting this group of children as "autistic disturbances" and proposed a new diagnostic category. In his observations of a unique psychiatric disorder, Dr. Kanner saw a forest while others before had seen only trees.

In the nearly 70 years since Kanner's first description of autistic disorder (autism), we have seen this diagnosis evolve considerably. This chapter will review the history of the diagnosis of autistic disorder. We will discuss the evolution of the diagnosis of autism from Kanner's work and through the various editions of the Diagnostic and Statistical Manual (DSM), with some speculation on the much anticipated fifth edition. Current terminology will be discussed from a historical perspective including the relatively new terms "Classic Autism," "Atypical Autism," and "High Functioning Autism." Finally, a general outline is provided for use in diagnosing individuals suspected to have an autism spectrum disorder.

Kanner's Autism

Leo Kanner, an Austrian born psychiatrist, founded the first psychiatry clinic devoted solely to the treatment of children at the Johns Hopkins University School of Medicine in 1930 (Alan Mason Chesney Medical Archives of the Johns Hopkins Medical Institutions n. d.). He was 36 years old at the time and had recently immigrated to the USA, having worked first in South Dakota before taking an offer to work at Johns Hopkins. In 1935, Kanner published the first textbook for child psychiatry (Alan Mason Chesney Medical Archives of the Johns Hopkins Medical Institutions n. d.). He wrote about various aspects of child psychiatry ranging from education to folklore; however, when he died in 1981, Dr. Kanner was best known for his work on establishing the diagnosis of autism.

Before Kanner published his seminal article, *Autistic Disturbance of Affective Contact* in 1943,

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no one had yet made a distinction between what Kanner called “Infantile Autism” and childhood onset schizophrenia (Matson 2008). The word autism, not coincidentally, was one of the “4 A’s” originally coined by Swiss psychiatrist Eugene Bleuler, who used it in reference to another term he also coined: schizophrenia (Gallo 2010). Bleuler took the term from the Greek “auto” meaning “self” to describe a focus on the self which he observed in individuals with schizophrenia (Gallo 2010). Persons with schizophrenia seem to actively withdraw from the outside world and enter a world marked by distortions of both perception and cognition (Gallo 2010). Kanner borrowed the term from Bleuler in order to describe children who appeared to have a similar self-turned focus (Gallo 2010).

Schizophrenia and Autism; Related but Unique Disorders

The connection between schizophrenia and autism is not purely based on the historical overlap of these diagnoses, but includes clinical connections that are observed in treating individuals with these two disorders. As Kanner noted, individuals with schizophrenia manifest a variety of negative symptoms including social withdrawal which make them appear clinically similar to individuals with autism. The symptoms related to social dysfunction in both disorders can also be severely disabling, and include limited motivation to engage in social interaction, flat affect, and the lack of social and emotional reciprocity (Woodbury-Smith et al. 2010). On tasks of social cognition, patients with both autism and schizophrenia show similar functional abnormalities in multiple brain regions, including the cerebellum, insular cortex, and fusiform gyrus (Meyer et al. 2011). In autism-related irritability, psychiatrists often prescribe antipsychotic medications, originally developed to treat schizophrenia (Woodbury-Smith et al. 2010; Melville et al. 2008). In both disorders, symptoms can be very resistant to both pharmacologic and psychotherapeutic intervention.

The long-term outcomes in both autism and schizophrenia were not known to Kanner when he made his initial distinction between the two disorders. Over time, further observations have been made by following these individuals longitudinally. Interestingly, it has been found that individuals with autism also commonly suffer from psychosis and are actually ten times as likely as the general population to develop new onset psychotic symptoms in a given year (Melville et al. 2008). Several genes have been discovered that may be associated with both autism and schizophrenia indicating, perhaps, a common neurodevelopmental pathway or disease process (Burbach and Van der Zwaag 2009). For example, some authors suggest that a common etiology of maternal infection or inflammation may be involved in both disorders (Meyer et al. 2011). Others have observed that individuals with autism have a significant decrease in life expectancy which is also characteristically seen in individuals with schizophrenia (Shavelle and Strauss 1998), although the mechanism underlying this outcome is not clearly understood.

Kanner made the crucial observation that individuals with autism differed from those with schizophrenia in that they lack a period of normal development prior to the onset of symptoms (Gallo 2010). This observation is the reason that autism is categorized as a pervasive *developmental* disorder. Symptoms of autism are present throughout early development and diagnosis is typically made in early childhood. Further differentiation includes the concrete and reality-based thought process seen in autism. In addition, hallucinations and delusions, which are the hallmark symptoms of schizophrenia, are often not appreciable in individuals with autism.

When brain imaging technology developed in the 1970s research methods turned to finding differences among and between individuals with mental illness. On a structural level, neuroimaging studies have shown that individuals with autism have increased white matter, gray matter and cerebellar white matter volumes (Stanley 2002). This is in contrast to gray matter reduction in the frontal and temporal lobes found in individuals with schizophrenia (Stanley 2002). Though there are some functional similarities in both patient populations, as mentioned previously, neuroimaging studies have noted significant structural differences.

In addition to differences in developmental history and neuroanatomy, there are also many distinctions between autism and schizophrenia in other domains. In 1972, Sir Michael Rutter published one of the most important articles to define differences in these disorders and enabled clinicians for the first time to see the distinction between them. He noted that, although genetic factors were prominent in both disorders, parents of children with autism were often highly functional, intelligent, and of higher social class (Rutter 1972). Schizophrenia, in contrast, is one of the most inheritable disorders in all of psychiatry. Genetic studies in autism show that schizophrenia is exceedingly rare in families with autism and vice versa (Rutter 1972).

Regarding cognitive functioning, individuals with autism are much more likely to suffer from intellectual disability than individuals with schizophrenia and individuals with schizophrenia are more likely to suffer from cognitive decline over the course of their lifetime (Rutter 1972). With respect to comorbid conditions, individuals with autism are more likely to have epilepsy (Rutter 1972). Regarding distribution within the population, autism differentially affects male children at a rate of 4:1 while the gender distribution in schizophrenia is evenly split between the two sexes (Rutter 1972). Observing disease course, marked remission of symptoms can occur in schizophrenia and remission is exceedingly uncommon in autism (Rutter 1972). Much of the evidence which supported Kanner's initial hypothesis did not become available until 30 years after his publication, when Rutter used additional research findings to fully differentiate the two disorders.

Initial Diagnostic Criteria for Autistic Disorder

Based on a series of 11 children (eight boys and three girls) described in his initial publication, Kanner provided the following observations which became his initial criteria for a diagnosis of autism (Jordan 1999; Kanner 1943).

Profound autistic withdrawal Kanner originally observed that his patients were "happiest when left alone, almost never cried to go with… mother, did not seem to notice… father's homecomings, and [were] indifferent to visiting relatives…" (Kanner 1943, p. 218). Clearly, Kanner considered social dysfunction to be the most essential diagnostic criteria for patients with autism. Many of the other criteria are derived from this initial feature. For example, a "*need for sameness*" is one way in which individuals with autism avoid acknowledging others, and the effect others have on changing the surroundings. A "*tendency to be overstimulated*" is one way in which the outside world intrudes on the patient's purposeful withdrawal. Deficiencies in *language* may be the result of individuals with autism lacking the motivation to interact effectively with others. Thus, Kanner understood that social withdrawal and a failure to relate to others had many overriding effects on the symptoms experienced by his patients.

Need for sameness Kanner noted that routines and the maintenance of an unchanging environment were important to his patients. He gives an example of one patient who repeatedly threads buttons in a particular order for no reason other than that this was the order in which he was originally taught (Kanner 1943). In Kanner's observations, disturbances in routine and environment often caused significant distress and led to violent outbursts. One way he conceptualized the need for sameness was that it promoted the integrity of the individual's world of solitude. In other words, in the absence of environmental change they could more effectively ignore the existence of others. That does little to explain why these children had restricted, repetitive, and stereotyped behaviors. In speaking, these individuals commonly used repetition in intonation, as well as in making sounds and phrases. Interestingly, Kanner's patients required the behavior of those around them to maintain the same type of repetition and consistency.

Excellent rote memory Kanner noted outstanding cognitive abilities in some of the children in his series, one of whose intelligence quotient (IQ) was upwards of 140. Four of the children in his study, incidentally, were the offspring of physicians. At the age of 2 or 3 years many of his subjects could recite a multitude of words, numbers, and poems which had very little meaning to anyone else (Kanner 1943). Kanner notes that many of the individuals in his series requested information from parents which was then incorporated into their long-term memory. He also notes that many of the parents spent a lot of time teaching their children by rote methods. Kanner implied that parents may have shared this information in order to compensate for lacking the opportunity to share other more meaningful experiences with their children.

Mutism or language that lacks communicative purpose Three of the patients in Kanner's case series were mute. Of the eight patients with verbal ability, words for them had a literal and inflexible meaning (Kanner 1943). He noted that many of his patients yelled nonsense words or phrases and other "irrelevant utterances" were a common part of their speech (Kanner 1943). Often words were used without the purpose of communication. Many of Kanner's patients had *echolalia,* or the repetition of words or phrases which lack an intended meaning. *Pronoun reversal* was also common. Abnormalities of speech were evident early in life and Kanner's patients frequently failed to meet developmental milestones.

Tendency to be overstimulated Kanner observed several sensory oddities in his series of patients. He reported that intense lights and sounds were a problem for them. Kanner felt that these stimuli were troubling to his patients because they intruded on the child's aloneness and could not be purposely avoided or ignored (Kanner 1943). Kanner also notes several of his patients had problems in feeding early in life that one may postulate to be related to a propensity towards overstimulation by textures and taste.

Skillful relationship with objects Kanner noted that many of his patients had dexterity with telephones, scissors and other objects, though they frequently used them without a meaningful purpose. His patients often were quite adept at completing tasks involving tools, but would only be able to complete them if the same pattern of behaviors was carried out in the same order. For instance, one of the children would be able to fetch something for his mother in another room but only if the object was in the exact place where the child had last found it. If the object had been moved, even within plain sight, he failed at this task. Many of the children in Kanner's series had spatial reasoning abilities that were above average. For instance, regarding another patient he says "I have seen her with a box filled with the parts of two puzzles gradually work out the pieces for each" (Kanner 1943, p. 230). Although his patients were quite adept at using tools, they often used these tools in a repetitive way which ultimately limited their usefulness.

Appearance of intelligence Kanner noted the appearance of intelligence in his patients which he felt was different from other severely impaired individuals who suffered from mental retardation. He described these individuals as "quiet, solemn, composed… self-sufficient and independent" (Kanner 1943, p. 230). Strangely enough, this was one of the reasons that Kanner recognized autism as unique from other previously defined disorders and thus felt it important enough to mention in his publication. Kanner saw a series of physically attractive and intelligent appearing patients with normal or above normal IQ. These children shared a number of other gifts including *good rote memory,* and a *skillful relationship with objects*. At the same time they were also severely socially impaired to be considered very limited in their ability to function in almost any setting. Many of these observations highlight Kanner's tendency to identify and focus on the strengths of the patients he treated.

Kanner's Revised Diagnostic Criteria for Autism

Later, Kanner revised and simplified his diagnostic criteria in order to develop a more general categorization method (Jordan 1999). His goal was to define the most basic features underlying the disorder. Kanner felt that some features of autism (such as repetitive language) could be explained as deriving from higher order symptoms (Jordan 1999). In 1956, Kanner proposed three criteria for the diagnosis of autism. These included extreme isolation, insistence on sameness, and an onset prior to 2 years of age. Simplifying these ideas even further, Kanner stated that the one central feature of autism was the patient's inability to relate to others from early on in life (Volkmar and Lord 1998). This concept, which he initially called "profound autistic withdrawal" and later referred to as "extreme isolation," was the highest order symptom that explained all of the others (Jordan 1999). Thus, in Kanner's eyes, the term "autism" was intended to fundamentally describe a disorder of social relatedness.

Kanner's Disproved Assumptions

It is notable that from his initial observations, Leo Kanner made several assumptions which later proved to be false. This is not meant to detract from the revolutionary accomplishment of his initial observations. To the contrary, many of these false assumptions have carried over to current practice and are still commonly held beliefs by mental health providers. We seek here to clarify some of these assumptions which lack empiric evidence.

Kanner assumed that children with autism had normal or above normal intelligence (Jordan 1999). More recent observations, however, show that around 75 % of individuals with autistic disorder also meet diagnostic criteria for intellectual disability (Volkmar and Lord 1998). Some research has sought to find strengths of individuals with autism based on Kanner's observations of superior memory. However, the scores of individuals with autism on cognitive tests of local verses global processing has been mixed without the clear advantage in so-called "rote memory" observed by Kanner (Spek et al. 2011). More recent estimates have shown that the so-called "idiot-savants," or individuals with autism or intellectual disability who display extraordinary talents in highly specialized areas, are exceedingly rare and constitute only around 1 in 2,000 individuals with autism (Heaton and Wallace 2004).

Another Kanner observation shown to be inaccurate was that autism is not associated with medical illnesses. Sixty years of observation and research have shown that this is also false. As was previously stated, as many as 25 % of children who are diagnosed with autism will go on to develop epilepsy (Volkmar and Lord 1998). Additionally, numerous correlations have been found associating autism with deficits in hearing, vision, prenatal exposure to valproic acid, and genetic conditions such as fragile X syndrome.

Early explanations for autism blamed parents and minimized biological factors. This may have had origins in Kanner's observations of parents of the children in his original case series. However, assumptions about the etiology of autism further developed as a response to his initial publication. "Refrigerator Mothers" who withheld affection and failed to bond with their children were believed to be coupled with overachieving though emotionally distant fathers in order to yield autistic offspring (Volkmar and Lord 1998). Later research repudiated the theory that autism was caused by a dysfunctional child-parent relationship, showing no increased incidence of autism in orphanages in which children were brought up deprived of human contact (Volkmar and Lord 1998). Many children who were raised in social isolation had delays in language development but lacked ritualistic behavior (Rutter and Bartak 1971). Although some of what Kanner originally observed has not weathered the test of time, it is difficult to overestimate Kanner's impact on the diagnosis of autism. We now understand autism to be a complex neuropsychiatric condition associated with diffuse central nervous system dysfunction and multiple medical conditions.

Diagnostic Progress Beyond Kanner

After Kanner's original proposal of a distinct diagnostic category for autistic disorder in 1943, many alternative diagnostic systems were proposed. Creak, O'Gorman, Rendle-Short, Rutter and Wing all proposed criteria during the 1960s and 1970s (Jordan 1999). Rutter summarized much of the prevailing opinion which emerged from the diagnostic debate in this list of four criteria which were published in 1971 (Jordan 1999; Rutter and Bartak 1971). These criteria included delay in speech, failure to develop interpersonal relationships, ritualistic and compulsive phenomena, and an onset before 30 months.

Delay in Speech

Rutter, like Kanner before him, noted many abnormalities in the speech of individuals with autism (Rutter and Bartak 1971). He identified pronoun reversal and echolalia as the most prominent features in the speech of individuals with autism. Rutter also noted a general paucity of speech reflecting little motivation to engage others in conversation. In addition, Rutter found that individuals with autism frequently had abnormalities in tone and pronunciation.

Failure to Develop Interpersonal Relationships

Rutter identified social dysfunction as the "key feature" of autism in agreement with Kanner's previous work (Rutter and Bartak 1971). In his paper, he provides several examples of how this feature is manifested, including poor eye contact, little variation of facial expression, and a lack of interest in people. He saw that individuals with autism lacked normal development of sympathy and empathy and did not effectively express their emotions. This was seen very early in babies preferring not to cuddle with parents and developing very little attachment to them. Later on, these same children did not spontaneously seek out others and did not engage in normal play.

Ritualistic and Compulsive Phenomenon

Rutter delineated four ways in which individuals with autism act in ritualistic or compulsive ways (Rutter and Bartak 1971). Some had an unvarying attachment to unusual objects. Others had restricted interests and still others quasi-obsessive ritualistic behaviors. Rutter also identified the resistance to change, which Kanner had initially identified as a separate diagnostic category, falling within the realm of ritualistic or compulsive phenomenon.

Onset Before 30 Months

Rutter noted that while the vast majority of patients developed symptoms of autism within the first year of their life, some patients developed symptoms later on (Rutter and Bartak 1971). He chose to restrict the diagnosis of autism to those individuals who presented symptoms prior to 30 months. Rutter somewhat arbitrarily chose this number since it captured the population of patients he identified to have autism and excluded other patients similarly impaired by other illnesses, such as early onset schizophrenia.

Standardized Diagnosis Within the Diagnostic and Statistical Manual

The Diagnostic and Statistical Manual of Mental Disorders (DSM) did not accept the diagnosis of autism until the third edition which was published in 1980 (Volkmar and Lord 1998; American Psychiatric Association 1980). This reflected the body of work Rutter had accumulated over the previous decade since his initial publication in 1971 (Volkmar and Lord 1998). Though initially called "Infantile Autism" in the *Diagnostic and Statistical Manual—Third Edition Revised* (DSM-III-R; American Psychiatric Association 1987) changed the name to autistic disorder and removed the onset requirement which was initially present in the DSM-III (Volkmar and Lord 1998). Aside from requiring the onset of symptoms prior to *36 months*, reinstituted after DSM-III-R, the criteria in the *Diagnostic and Statistical Manual—Fourth Edition* (DSM-IV; American Psychiatric Association 1994) reflected the core ideas proposed by Rutter. The three symptom clusters of social dysfunction, speech delay, and ritualistic or stereotypic behavior were all preserved in this version, as well as in the *Diagnostic and Statistical Manual—Fourth Edition Text Revision* (DSM-IV-TR; American Psychiatric Association 2000). As Kanner understood, autism fundamentally is a disorder of social relatedness. This emphasis is reflected by requiring two criteria from this symptom cluster while requiring just one each from the other clusters (American Psychiatric Association 2000).

Diagnostic criteria for 299.00 autistic disorder (American Psychiatric Association, 2000).

(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. 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. 2. qualitative impairments in communication as manifested by at least one 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. 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 is abnormal either in intensity or 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: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

(C) The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

As clinicians sought to further define what constituted a diagnosis of autism, they encountered numerous individuals who met some but not all of the required criteria. As a result, a new diagnostic category, pervasive developmental disorder not otherwise specified (PDD NOS), was created.

Pervasive developmental disorder not otherwise specified PDD NOS is another diagnosis which first appeared in the DSM-III (Buitelaar et al. 1999). PDD NOS is known by several other names including "atypical PDD" and "atypical autism" (Volkmar and Lord 1998). The DSM-III and DSM-III-R defined this term quite vaguely as a severe social impairment which does not meet criteria for autistic disorder. The DSM-IV, which defined new diagnoses of Asperger's Disorder, Rett's Disorder, and Childhood Disintegrative Disorder, defines PDD NOS as a severe social impairment not meeting criteria for any of the other PDD (Volkmar and Lord 1998). According to the DSM-IV-TR, possible reasons for selecting this diagnosis and thus reasons that the patient would not be diagnosed with autistic disorder, include such things as later age of onset or more commonly atypical or subthreshold symptomatology (American Psychiatric Association 2000). This can be primarily manifested in three scenarios. There are individuals with PDD NOS who have *mild* social dysfunction but significant speech delay and stereotypic movements (Buitelaar et al. 1999). Another possibility is that individuals have significant social dysfunction but lack either speech delay or stereotypic movements (Buitelaar et al. 1999). Finally, this category may include individuals which have an onset of the disorder after 36 months of age (Buitelaar et al. 1999).

Asperger's disorder At the same time that Kanner defined autism, another Austrian named Hans Asperger published a case series of four children suffering from a slightly different type of social impairment in Austria in 1944 (Volkmar and Lord 1998). In contrast to Kanner's subjects, these children had higher language capacity and were often excessively verbal. Also unlike individuals with Kanner's definition of autism, many described by Asperger would seek out others in attempt to engage in social interaction. They would talk in depth about a narrow range of topics much as a "little professor." When speaking about their specific interests, these individuals had much difficulty appreciating social cues to stop speaking or to invite reciprocal dialog.

Asperger observed his condition to be marked by delays in social maturity, to occur almost exclusively in males, to be associated with strong cognitive skills and to run in families (Volkmar and Lord 1998). Ironically, in order to describe the social dysfunction experienced by these individuals, Asperger used the same word as Kanner (and Bleuler before him). For 40 years this condition was referred to as "Autistic Personality Disorder," a phrase coined by Asperger and first published in German (Attwood 2006). Asperger's initial case series went largely unnoticed in English-speaking countries until a review of his work was published by Lorna Wing in 1981 (Attwood 2006). Wing noted some differences in a subgroup of individuals being classified as having autism. She recognized that they were similar to individuals seen previously by Asperger, and invented the term "Asperger's Disorder" (Attwood 2006). It was not until 1991 that Asperger's writing was translated into English by Uta Frith and became widely disseminated through English speaking circles (Attwood 2006).

Diagnostic criteria, which pre-dated the DSM-IV, were proposed by Christopher Gillberg in 1991 (Atwood 2006). Gillberg's criteria included social dysfunction, narrow interest, compulsive need to introduce interest to others, peculiar or pedantic speech, deficiency in nonverbal communication and motor clumsiness (Attwood 2006). Asperger's Disorder was overlooked by the first three editions of the DSM but ultimately included in the 4th (Szatmari et al. 1995). Diagnostic criteria in the DSM-IV are dissimilar to those proposed by Gillberg, due to the omission of motor clumsiness and speech peculiarities. The DSM-IV includes no reference to pedantic speech or the need to introduce their interest to others. Similar to the way in which the DSM had defined autistic disorder, two symptoms from the social domain emphasize that Asperger's Disorder is primarily a social disturbance. Also, the social dysfunction and stereotypic behavior criteria are identical in phrasing to the same domains used to define autistic disorder. Many clinicians find that the unique variation of social dysfunction and the specific narrowed interests seen in Asperger's Disorder are distinct from autism and prefer to use Gillberg's criteria for this reason (Attwood 2006). As noted initially by Asperger, exclusion criteria in the DSM-IV include language and cognitive delay.

Diagnostic criteria for 299.80 Asperger's disorder (American Psychiatric Association 2000).

(A) Qualitative impairment in social interaction, as manifested by at least two of the following:

1. 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
2. failure to develop peer relationships appropriate to developmental level
3. 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 to other people)
4. 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:

1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. apparently inflexible adherence to specific, nonfunctional routines or rituals
3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
4. 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 schizophrenia.

Differential diagnosis With the similar diagnostic phrasing used in the DSM-IV the question arises as to whether these three disorders are truly unique or just variations on a spectrum of disturbances marked by social impairment. According to DSM-IV definition, individuals lacking significant language delay but having impairment in social relatedness and stereotypic movements have Asperger's Disorder, though prior to the 4th edition of the DSM they would have been diagnosed with PDD NOS. Significant confusion has persisted in differentiating PDD NOS from Asperger's Disorder and misdiagnosis is common (Volkmar and Lord 1998). Additionally, as it is currently defined, Asperger's Disorder is unique from Autistic Disorder only in the lack of abnormal language and cognitive development. There arises a problem in distinguishing individuals with Autistic Disorder who have normal intelligence or so called "High Functioning Autism" from individuals who have Asperger's Disorder which is not resolved by the DSM. By excluding many of Gillberg's defining criteria, many clinicians feel that the DSM-IV inadequately describes the unique pattern of pathology seen in individuals with Asperger's Disorder (Attwood 2006). This debate however, may be a moot point with anticipated changes the DSM-V which are discussed later.

Rett's disorder and childhood disintegrative disorder The two remaining diagnosis in the PDD category of DSM-IV are Rett's Disorder and Childhood Disintegrative Disorder. Rett's Disorder (also known as Rett Syndrome) is a rare disorder first observed by Andreas Rett in 1966 and described in a case series of 22 female individuals (Haas 1988). According to the largest patient registry in the world, the prevalence of Rett's Disorder is estimated at 1 per 22,800, making it 36 times less common than autism (Chakrabarti and Fombonne 2001; Kozinetz et al. 1993). Rett observed females who initially had normal development, but later developed stereotypic movements, decelerating head grown, mental retardation as well as a loss of social and language abilities (American Psychiatric Association 2000). Similar to Asperger's work, Rett originally published in German and the disorder did not reach widespread recognition by English speaking audiences for several decades until a larger case series was published in English in 1983 (Haas 1988). Several studies have found an association between Rett's Disorder and a gene mutation (MECP2) found on the X chromosome (ADAM Medical Encyclopedia 2011).

Childhood Disintegrative Disorder (also known as Heller's Syndrome) was first described by Heller in 1908 and initially called Dementia Infantilis (Volkmar 1997). Heller described a case series of six children who had developed normally but subsequently developed a severe regression and appeared to have symptoms similar to autism (Volkmar 1997). The disorder was included in the DSM-III but amid significant controversy over whether it should be considered a PDD or a Neurodegenerative Disorder (Volkmar 1997). The disorder disappeared from the DSM-IIIR due to removal of the onset criterion for

Autistic Disorder. It then reappeared in the DSM-IV with reinstatement of this criterion (Volkmar 1997).

The “Autism Epidemic” and the Evolving Diagnosis of Autism

Many terms within the field of autism reflect a changing understanding of the topic in the field of child psychiatry and psychology. Initially there existed only one category known alternately as “infantile autism,” “autism,” “autistic disorder,” “Kanner’s autism” and “classic autism.” Included in this category is the newer term of “high functioning autism” (HFA). Initially, HFA referred to an individual with autistic disorder and normal language and cognitive function. Over time, this term came to be used to include those with Asperger’s disorder, meaning that these individuals never had a *delay* in speech. Next, there diverged a separate but related category known as “atypical autism” which became known as “PDD NOS.” This category described everything that appeared to be like autism but the symptoms do not meet full criteria for autistic disorder. “Asperger’s disorder,” “Rett’s disorder,” and “childhood disintegrative disorder” (also known as “Heller’s syndrome”) were contained within this diagnosis until they appeared in the next version of the DSM. Together with autistic disorder and PDD NOS, the disorders described by Asperger, Rett, and Heller form a group of related disorders known as “PDD”or “autism spectrum disorders” (ASDs). It is important to note the plural tense of these two terms as they do not define a single diagnosis, but rather multiple diagnoses contained under the same category.

Not surprisingly, as diagnostic criteria have changed over the years so has the prevalence of autism and related disorders. Coincidental with some of these changes has been the so-called “autism epidemic” which saw rates of autism incidence in the USA increased sevenfold between 1990 and 2001 (Hertz-Picciotto and Delwichi 2009). The increasing incidence of autism has many possible factors including changes in criteria, increased public awareness, changes in diagnostic practices, methodology, as well as possibly a true rise in incidence (Hertz-Picciotto 2009). While initially excluding individuals with intellectual disability, for instance, Kanner’s first set of criteria left out many of the individuals included in our present-day understanding of the disorder. Additionally, adults who would have been previously classified as having schizophrenia prior to the introduction of the autism diagnosis were typically not then re-evaluated in 1943. As information on developmental milestones became widely available and diagnostic criteria entered public awareness, parents and primary care doctors gained a much greater awareness of developmental disorders. With the establishment of PDD NOS as a diagnostic category, the inclusion of sub-threshold individuals dramatically increased the number of children being diagnosed with an ASD (Buitelaar et al. 1999). Despite the availability of information, however, public understanding about the differences between autistic disorder, PDD NOS, and Asperger’s disorder remains limited.

Changes in the DSM-V

Given the difficulty in differentiating autistic disorder from Asperger’s disorder, and PDD NOS and given the questionable utility in using these categories to describe what many feel is a spectrum of related disorders, Asperger’s disorder and PDD NOS have been excluded from the newest version the DSM (American Psychiatric Association 2013). The requirement for speech delay has been removed as a specific requirement, though it is explained that failure in back and forth conversation can be evidence of lacking social-emotional reciprocity. In the stereotypic behaviors category an additional item has been included to describe hyper-or hypo-reactivity to sensory input. Like previous definitions, onset must be in early childhood and the disorder must be severe enough to impair functioning.

Autism Spectrum Disorder (American Psychiatric Association 2013)

a. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

1. Deficitis in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

b. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:
   1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
   2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route, or eat food every day).
   3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
   4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual).

c. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

d. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

e. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and ASD frequently co-occur; to make comorbid diagnoses of ASD and intellectual disability, social communication should be below that expected for general developmental level.

In addition, there is a new diagnostic category in the new version of the DSM, social communication disorder, which may also absorb some of the individuals previously considered to be on the mild side of the autism spectrum (American Psychiatric Association 2013). Specifically, this disorder may come to describe individuals who are currently diagnosed with Asperger's disorder or PDD NOS but have milder social dysfunction. Individuals who are diagnosed with social communication disorder must have difficulty with the social aspects of both verbal and nonverbal communication and this must impair their ability to be understood, causing significant limitations in social participation, academic achievement, or occupational performance. These individuals will have difficulty with the practical or pragmatic use of language, as opposed to the structure and grammar associated with language.

Impact of the Changes in Diagnostic Criteria

Some discussion should be offered over whether or not these diagnostic changes are appropriate. A recent study by Worley and Matson (2012) applied DSM-V criteria to individuals previously identified as having a PDD under the DSM-IV-TR. Worley and Matson (2012) assessed 360 patients, age 3–16 years, and applied both DSM-IV-TR and the DSM-V criteria to them with the assistance of caregiver report. A minority of patients did not meet criteria for having ASD by either version of the DSM, and these patients were excluded if they had another disorder which may account for their symptoms (such as intellectual disability, social phobia, etc.). Ultimately, Worley and Matson found that one-third of patients who met DSM-IV-TR diagnosis for an ASD did not meet the diagnostic criteria under DSM-V.

A related article recently published in the *New York Times* also speculates about the potential impact of changing criteria on patients currently diagnosed with ASD in the DSM-IV-TR (Carey 2012). The article cites unpublished data in which 55 % of these patients did not meet criteria for ASD as defined in the DSM-V. Of patients previously diagnosed with autistic disorder, 25 % did not meet DSM-V criteria. More dramatic, is that 75 % of patients previously diagnosed with Asperger's disorder and 85 % of those with PDD NOS did also not satisfy diagnostic criteria by the new standards in the DSM-V. Although not yet subjected to peer review, the data published in the New York Times is concerning as it suggests that patients previously diagnosed with an ASD, especially those with Asperger's disorder and PDD NOS, may no longer meet diagnostic criteria.

Two additional articles published recently have sought to test the validity of the DSM-V criteria of ASD. Mandy et al. (2012) assessed 708 children diagnosed previously with a PDD using the DSM-V criteria for ASD and the developmental, dimensional, and diagnostic interview. The children in this sample were all verbal and exhibited varying severity of symptoms. The authors compared the newly constructed two factor model of the DSM-V (social-communication deficits and restricted repetitive behavior) to the three factor model of the DSM-IV-TR (social impairment, language delay, and repetitive behavior). The DSM-V two-factor model was found to be a superior fit (Mandy et al. 2012), even for these higher-functioning children. Furthermore, Mandy et al.'s (2012) results supported the inclusion of sensory abnormalities as part of the category of repetitive and restrictive behaviors.

In the second study, Frazier et al. (2012) also assessed the validity of DSM-V criteria by looking at 14,744 siblings of children with ASD collected in a national autism registry (8,911 ASD and 5,863 non-ASD). Frazier et al. (2012) found the specificity of this model to be greater than the DSM-IV-TR criteria, indicating that fewer patients without the disorder would be incorrectly diagnosed. Sensitivity, on the other hand, or the likelihood of correctly identifying patients who have the disorder, was lower. In his study, Frazier found there was approximately a 90 % overlap of diagnosis, a number he suggested would improve with a more "relaxed algorithm" (Frazier et al. 2012, p. 28).

The primary concern with the changing criteria is that some individuals may no longer be able to access the services that they need and have previously received. The reality of how many individuals with a current diagnosis will fail to meet the new DSM-V criteria for ASD remains debatable but of particular concern would be individuals with Asperger's disorder who may no longer meet criteria under the DSM-V. Some evidence suggests that individuals with Asperger's disorder have a higher rate of mood disturbance, violent behavior, and psychosis than individuals with autistic disorder (Arora et al. 2011). Additionally, patient's with Asperger's disorder, having normal cognitive and language functioning, could be argued to be better candidates for psychotherapeutic services such as social skills training. Of course, many of the patients who currently are diagnosed with Asperger's disorder will likely meet DSM-V criteria for ASD. However, many people with this diagnosis, as well as their parents, have grown emotionally attached to this diagnosis. For some of these people, having Asperger's disorder means that they have a severe social dysfunction, but they are not "Autistic." Perhaps because of the requirement of normal IQ and speech, Asperger's disorder has a higher status in the eyes of the public. There is little doubt that the removal of this diagnosis from DSM-V may cause considerable concern among parents and the individuals themselves.

The Challenge and Importance of Early and Accurate Diagnosis

The issue of establishing a clear and definitive diagnosis in individuals with an ASD (comprising autistic disorder, PDD NOS, and Asperger's disorders as defined in the DSM-IV-TR) has many challenges. The process of diagnosing an ASD is filled with variability and thus is prone to error. This variability exists in the type of provider, their education, their evaluative process, their use of standardized objective measures, the weight of parent report and the role of patient observation in the diagnosis of ASD. Equally significant is the variability that exists within individuals, their intellectual and social functioning, their interests, thoughts, emotions, behavior, and self-awareness. Add to these factors the variability in the definition of these diagnoses over time and still to come, and it is not surprising that many providers are concerned that they are not equipped to diagnose ASD. In clinical practice, unsystematic approaches to gathering information cause inconsistencies in the application of DSM criteria and hamper the ability of clinicians to effectively diagnose ASD. And yet, as we will discuss, it is possible to use both objective and subjective criteria in a systematic way in order to obtain an accurate diagnosis of an ASD in almost all individuals.

Accurate diagnosis of an ASD is important for many reasons. Diagnosis provides a framework from which to access the literature and structure treatment based on sound science. Early diagnosis, as we shall see, leads to improved outcomes in these individuals. Ultimately, the diagnosis of an ASD allows individuals to effectively access needed funds in order to finance medications and medical services. However, care should be taken prior to labeling individuals with an ASD due to unintended consequences.

Individuals often find comfort in having a name given to the constellation of symptoms which leads them to present to the office of a mental or medical health care provider. Newly diagnosed individuals with ASD are given permission to consider that some of the difficulties they experience are the result of a brain condition over which they have no control. Similarly, parents of individuals with ASD feel validated by a diagnosis which explains their child's symptoms without blaming them or their parenting. The diagnosis of ASD tells parents that a medical authority believes the child's behavior is a significant problem. Establishing an accurate diagnosis is therefore crucial to establishing a therapeutic alliance with both individuals and caregivers.

Fundamental to the practice of medicine and psychology is the identification of a correct clinical diagnosis in order to guide and manage treatment. Both pharmacologic and psychotherapeutic interventions, however, are not without side effects, as well as significant commitments of time and money. In order to justify the risk and cost involved, prescribing practices should be dictated by sound research and a clear benefit for the individual patient must be identified and effect quantified. In the field of child psychiatry, diagnosis is a fundamental inclusion criterion in researching the efficacy of pharmacology and psychotherapy. Accurate diagnosis based on objective and subjective information is crucial for accessing and applying this research and practicing evidenced based medicine.

The diagnosis of ASD can be a gateway to much needed financial resources, social services, and medical care. A recent study showed that individuals with an ASD had to spend between US$ 4,110 and US$ 6,200 more on health care than those without an ASD, four to six times the amount spent by the average health-care consumer (Shimabukuro et al. 2008). Thankfully, individuals with ASD may qualify for community-based services through Medicaid and associated waivers. Access to these services is often the motivating force in individuals and caregivers seeking the diagnosis of an ASD and the granting of access to utilize these services is often the most dramatic contribution health-care providers can make to an individual's care. Because resources are limited, it is the responsibility of medical providers to be judicious in their diagnosis of an ASD in order to reserve funds and services for those individuals who are significantly and functionally impairment.

Early intervention in ASD has consistently been shown to improve outcomes in multiple domains, though barriers exist to obtaining a diagnosis that is both early and accurate. A randomized controlled trial funded by the National Institute of Mental Health and published in *Pediatrics* last year randomly assigned 48 children age 18–30 months diagnosed with autistic disorder to control or intervention groups (Dawson et al. 2010). The intervention consisted of intensive behavioral therapy (the Early Start Denver Model) and was found to significantly improve cognitive test scores, adaptive behavior, and social functioning. In another study, brief parent training consisting of just three basic 2 h sessions was shown to markedly improve communication skills in pre-school children with autistic disorder (Coolican et al. 2010).

Typically, however, diagnosis of autism occurs closer to school age. In one study, the median age of diagnosis of an ASD was found to be 6.1 years in females and 5.7 years in males (Shattuck et al. 2009). Lower cognitive functioning and the presence of regression (in addition to being male) all predicted earlier diagnosis of these individuals. This illustrates the fact that more severely impaired individuals are brought more readily to the attention of the medical establishment. Delays in diagnosis may be due to multiple factors in both individuals and the health-care system in which they live. Improving the outcome of individuals with ASD thus will involve overcoming these barriers to accurately diagnose at an early age.

It is important to keep in mind that after diagnosis of an ASD is obtained, there may be unfavorable consequences. The stigma attached to mental illness, though often unintended, invariably leads to stress through discrimination in work, social, and academic settings. Teachers, for instance may demand less from children with a known ASD diagnosis in social situations or may call on them less in class which may in turn give them less of an opportunity to engage in the learning process or to develop socially. Despite the fact that individuals with ASD qualify for valuable services through the schools and Medicaid waivers, the diagnosis itself is considered a "preexisting condition" and may make private insurance more expensive. During the lengthy process of applying for the Medicaid waiver, which may last up to several years in some states, individuals must rely on private insurance or pay out of pocket expenses for needed treatments, leading to decreased access to care. Anticipating these unfavorable consequences can lead parents to avoid evaluation of children with suspected ASD, continuing them in educational environments which do not meet their specific needs, delay diagnosis, and ultimately prolonging the many frustrations that both individuals and caregivers face.

Diagnostic Process

Multiple tools are available to clinicians seeking to diagnose individuals with ASD. These include both subjective and objective measures and it is important to understand the difference between them. Subjective measures refer to a person's experience of the world, including their thoughts, feelings, opinions, and observations. Patient or caregiver report would be considered a subjective measure. Objective measures refer to those things outside of a person's experience which can be observed and quantified by an outside source. In the most basic way, the Mental Status Examination is meant to be an objective examination tool available to mental health providers. Grodberg (2011) recently proposed an eight item Autism Mental Status Examination (AMSE) specific for use in this patient population. The eight items on the AMSE include eye contact, type of interaction, shared attention, language, pragmatics, repetitive behaviors, preoccupations, and unusual sensitivities (Grodberg et al. 2011). Many other scales, as we will discuss, are available as well. While subjective measures are more prone to bias by the person providing the information, objective measures are more biased by the person who is administering and observing the test. Both subjective and objective measures are equally important parts in unraveling the diagnostic dilemma of individuals with suspected ASD and each is incomplete without the other.

It may be argued, and should be admitted, that there are no unbiased and purely objective measures available for diagnosis of psychiatric disorders and ASD are no exception to this rule. There is no blood work, genetic testing, brain imaging, or other strictly objective tests indicated for every patient suspected of having an ASD. While these tests are all frequently performed and have utility in subgroups of individuals with an ASD. The development of autism-specific scales and measures, such as the Autism Behavior Checklist (Volkmar et al. 1988), Childhood Autism Rating Scale (Schopler et al. 1980), Autism Diagnostic Interview (Couteur et al. 1989) and Autism Diagnostic Interview-Revised (Lord et al. 1994) as well as the Autism Diagnostic Observation Schedule (Lord et al. 2000), are attempts to create more objective measures and to eliminate bias in the diagnosis of an ASD.

The importance of a systematic approach to obtaining both subjective and objective information cannot be emphasized enough. Interviewing individuals and caregivers in a systematic way helps to ensure that all of the key historical information is obtained and available for an informed diagnosis. Observing in a systematic way allows for easy comparisons between individuals and typically-developing individuals of the same age. Recording observations in a systematic way minimizes error and makes it less likely that valuable information is lost. In addition to note taking, an organized system of preserving the medical record makes it easier to look back on patient charts at a later time in order to find similarities and differences among groups of individuals. Thus, good research and sound science go hand in hand with a systematic approach to patient care.

Organizing a psychiatric interview and performing mental status examination of individuals suspected to have ASD deserves some explanation. The variability that exists within mental health providers and also among individuals and their families makes the diagnostic process prone to error. Therefore, it is beneficial to mention a few tips for gathering both a *subjective* history and an *objective* mental status examination that enable clinicians to perform these operations in a systematic way.

The consistency in the manner in which the clinician dresses, behaves, and interacts with individuals is important to eliminating confounding variables from the interview and observation process and is particularly important in individuals with ASDs. For instance, a clinician who is trying to manage a particularly heavy schedule may observe a lower capacity for meaningful speech in individuals than on a lighter day. Without sufficient time, important parts of the history may be overlooked. Similarly, consistency in dress in addition to technique is important for gathering reliable information. If the clinician decides to dress differently one day (and wears very shiny shoes for instance) he or she may find that individuals have very poor eye contact and seem to be staring at the shoes. Thus the clinician has altered the observed behavior of his patient through his appearance. These examples illustrate how a systematic approach may remove extraneous variables in gathering both subjective information (patient history) and objective information (patient eye contact and capacity for meaningful speech) which maximizes the likelihood of an accurate diagnosis.

Conclusion

Understanding the historical context of ASD and the current practice of these concepts allow us to better understand the direction of this burgeoning field. Knowing the subtleties and distinctions of subcategories within the autism spectrum is important for accurate diagnosis, though this may change with the next publication of the DSM. Good diagnosis involves using a systemic approach which removes variability to the greatest extent possible and utilizes both subjective and objective measures. Early and accurate diagnosis is important to improving the care of individuals with an ASD. Thoughtful examination of the historical context in this field is one way for clinicians to hone diagnostic skills and to ultimately improve patient care.

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2

Autism Spectrum Disorders: Several Disorders on a Continuum or One?

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Keywords
Diagnosis · Spectrum · Continuum

In 1943, Leo Kanner described 11 children as having come into the world without the usual disposition to make social contact, a condition he called *early infantile autism* (Kanner 1943). In his description of these 11 children, Kanner noted that despite limited interest in the social world, they were highly engaged with nonsocial aspects of the environment and had difficulties with change. In 1944, Hans Asperger, an Austrian pediatrician, described four children who had difficulty integrating socially into groups despite seemingly adequate cognitive and verbal skills, a condition he called *autistischen psychopathen im kindesalter,* which translates in English to "autistic personality disorders in childhood" (Asperger 1944). Asperger was apparently unaware of Kanner's classic description of autism, thus the focus both authors made on the marked social dysfunction is remarkable and speaks to the centrality of social deficits as the defining feature of these disorders. Beginning with Wing's seminal work and description of the condition (Wing 1981), interest in Asperger's syndrome has increased greatly, leading to inclusion of Asperger's syndrome in American Psychiatric Association's (APA) *Diagnostic and Statistical Manual of Mental Disease,* fourth edition (DSM-IV; American Psychiatric Association 1994) and the World Health Organization's (WHO) *International Classification of Disease,* tenth edition (ICD-10; World Health Organization 1992) culminating in the recognition of a broad spectrum of individuals with social disability that form what we now term autism spectrum disorders (ASDs).

The current diagnostic taxonomy of the DSM-IV (APA 1994) and the ICD-10 (WHO 1992) place autism, Asperger's disorder, and three related social disabilities in the category of pervasive developmental disorders (PDDs). The three most common PDDs (autistic disorder, Asperger's disorder, and pervasive developmental disorder, not otherwise specified (PDD-NOS)), are often referred to more generally as "autism spectrum disorders". Autistic disorder is characterized by severe social deficits, impaired communication skills, the presence of restricted and repetitive behaviors, and an onset in early childhood. Asperger's disorder differs from autistic disorder in (a) omission of the diagnostic criteria in the communication domain; (b) absence of a requirement for onset prior to age three; and (c) addition of criteria specifying impairing dysfunction, absence of a language delay, and absence of deficits in cognitive development or nonsocial adaptive function. Furthermore, a precedence rule indicates that, to meet criteria for Asperger's disor-

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der, one cannot meet criteria for another specific PDD. PDD-NOS denotes a subthreshold form of autism, or a manifestation of PDD that is atypical in terms of onset patterns or symptomatology such that defining features of other PDDs are not met. Diagnosis requires that the individual exhibits autistic-like social difficulty along with impairment in either communication or restricted and repetitive interests or behaviors.

Most people now consider autism to be a spectrum of disorder(s). However, there has been much controversy regarding the distinctiveness of the different subtypes and the ability of clinicians to accurately and reliably distinguish between them (Charman et al. 2009; Baird et al. 2003; Volkmar and Klin 2005; Lord and Bishop 2009). In this chapter, we set out to address, at least in part, some of this confusion and provide a systematic way of thinking about the classification of disorders that reside along a spectrum. We begin the chapter by providing an overview of two classification approaches (categorical and dimensional), which is followed by a discussion of statistical techniques that can be used to subtype and classify disorders. Next, a description of the current categories of PDDs is provided along with a discussion of several pertinent areas of debate. The chapter then describes the changes in diagnostic criteria in DSM-5 and a discussion of the implications that the changes might bring. We close the chapter by providing our concluding thoughts and areas for future research.

Categorical vs. Dimensional Classification Approaches

A host of considerations arise in the development of any approach to classification. Major considerations include overall goals and purpose (e.g., is the primary purpose rigorous definition for research purposes or broader definitions for clinical use? Will subthreshold conditions be included and if so how? Can information on other conditions (medical conditions or comorbid psychiatric/developmental ones) also be coded? Approaches to diagnosis (both categorical and dimensional) lose their value if they are overly broad or overly narrow. Similarly, if the intended use is for research, definitions must be more specific and detailed while for general clinical, use a different approach might be used. The US (DSM) system has consistently been “dual use” while the international (ICD) approach has different volumes of detailed research criteria as well as a more general and descriptive cynical guideline (Rutter 2011).

Categorical Approaches

Medical classification systems arose in the context of important public health issues (e.g., controlling infection) and an awareness of the need to monitor public health at a macro level (e.g., causes of mortality). These systems tend to be categorical, although dimensional approaches can also be used quite readily (see Rutter 1992; Volkmar et al. 2005; Rutter 2011). Both DSM-IV and ICD-10 adopt an explicit dichotomous categories approach (i.e., an individual does or does not have a specific disorder) although they differ in some respects (as noted above in the dual approach vs. unitary approach and also in some other ways as in the overall approach to comorbid conditions).

The DSM-IV and ICD-10 categorical approaches are very closely related and both definitions were based on the results of a large international field trial (Volkmar et al. 1994). As part of this, 21 sites with more than 100 raters provided information on nearly 1,000 cases who were included if autism was reasonably thought to be a part of differential diagnosis. The sample exhibited a range of ages, levels of functioning, and severity, and in most cases, raters felt the quality of information available to them for their ratings was good to excellent. Based on a series of preliminary data reanalyses, it was agreed that the system developed for autism should aim to have a reasonable balance of sensitivity and specificity across the IQ range as well as age. Interrater reliability of individual criteria was generally good to excellent (see Volkmar et al. 1994). The final definition included 12 criteria grouped in three categories (social, communication-play, and restricted interests and behaviors) with a minimum requirement of a total of six criteria, two of which had to be social ones (the latter in view of the strength of social features in predicting diagnosis). In addition, data were felt to be sufficient to include several disorders "new" to DSM-IV and/or ICD-10. These included Asperger's disorder, Rett's disorder, and childhood disintegrative disorder (see Volkmar et al. 1994, 2005 for a review). This approach has proven relatively robust probably because it is readily applicable and because the system is the same for both DSM-IV and ICD-10. The large increase in research papers, from about 300 published in 1992 to over 2,400 during 2012, is a testament to the utility of the system. At the same time, issues have been raised, particularly about the definition of Asperger's disorder (Volkmar and Klin 2005), and major changes are planned for the upcoming revisions to the DSM, which are discussed later in this chapter.

Dimensional Approaches

Even with a categorical approach there is an awareness that symptoms may exist on a dimension, e.g., of function or of dysfunction. For example, blood pressure, IQ, height, and weight are all dimensional measures, but by convention (ideally based on good data), some threshold may be selected for a categorical diagnosis like hypertension and intellectual disability. In this regard, dimensional approaches offer many advantages.

Dimensional approaches in autism can take various forms. These include the use of standardized normative assessments (e.g., of intelligence, communication, motor development, adaptive behavior; Klin et al. 2005). Some work has even used a normative measure of social competence, for example, on the Vineland Adaptive Behavior Scales (Volkmar et al. 1987). Other instruments focus more on abnormal behaviors or development, e.g., the Childhood Autism Rating Scale (Schopler et al. 1980) which assess 15 kinds of behaviors on a continuum of severity ranging from 0 (normal) to 4 (severely autistic). More recently, the approach as in the Autism Diagnostic Schedule (ADOS; Lord et al. 2000) and the Autism Diagnostic Interview -Revised (ADI; Lord et al. 1997) has been to focus on assessments that can be related to (and thus operationalized in greater detail) formal categorical criteria. The ability to "cross walk" back to categorical criteria has many advantages for research purposes. On the other hand, instruments that take considerable training may be impractical for general clinical use, i.e., a general practitioner who wants a simple description of the condition and clinical guidelines would not be able to obtain advanced training easily, and thus might opt not to use standardized instruments for diagnosing autism in their practice. For that individual another set of issues arise in terms of guidelines for screening (and practice; Hyman and Johnson 2012).

Screening instruments Issues in the development of screening approaches to autism raises other issues (see Barton et al. 2012). Level I screening is intended for general developmental screening while Level II screeners focus more specifically on autism. A recent trend has been the encouragement of simple screeners useful in general practice for assessment of relatively young children (see Coonrod and Stone 2005 and Hyman and Johnson 2012); however, practical issues arise given the relatively small number of clearly relevant developmental and behavioral milestones observed in the youngest children (see Chawarska and Volkmar 2005; Volkmar et al. 2005, 2007). A number of excellent instruments are available (see Barton et al. 2012; Conrod and Stone 2005; Johnson and Myers 2007), although as Hyman and Johnson (2012) have emphasized, there are many areas of potential difficulty with only a small proportion of cases that screen positive eventually receiving services. Another problem is that issues of diagnosis can be particularly challenging for infants under three and particularly under 18 months when some features (often social and communication ones) may be present but restricted interests have yet to develop to the threshold level (e.g., the child with unusual sensory interests who does not yet manifest the range of restricted interests typically required). Another set of challenges arise for screening relative to older individuals (those above age three in this context) and to those at the two "ends" of the spectrum in terms of cognitive functioning (see Campbell 2005, Coonrood and Stone 2005; Reilly et al. 2009). A few behaviors, e.g., attachments to unusual objects, are predictive at one age but not another, and for this reason, this symptom was not used in the final DSM-IV/ICD-10 definitions. For all, screening instruments, many different issues arise pertaining to the intended user and context (parent report, observation, or both). For parent report, issues of parental perception, age of child, and problems like "telescoping" effects are a complication in terms of reliability and the potential significance of low-frequency behaviors, particularly in older children (Lord and Corsello 2005). Observational approaches have their own limitations, including the potential of missing important behaviors of low frequency but diagnostic importance, thus giving rise to issues with reliability and validity.

Statistical Approaches to Diagnosis

The assignment of individuals to known diagnostic categories and the determination of whether such categories exist within a class of disorders are two distinct but complementary questions that can both be addressed using statistical methods. The main difference between the two approaches to diagnostic categorization is in whether a set of categories already exists, and one wishes to determine how well the categories describe individuals in different groups and how well they are separated, or if no such categories exist, and one attempts to infer them from the data if possible. The former is termed *classification* and the latter *clustering* or *subtyping,* and the distinction between them parallels a fundamental difference in statistics and machine learning between *supervised* and *unsupervised* learning methods (Hastie et al. 2009). Supervised methods rely on group labels to "supervise" or oversee the partitioning of data into known subgroups, utilizing the differences in the data between the known subgroups to best distinguish between them. Unsupervised methods, on the other hand, use only the structure of the data itself to determine the presence and the number of subgroups.

Included in the class of supervised methods are the classification methods familiar from most introductory statistics courses, such as logistic regression (Agresti 1990; Dobson 2001) and Fisher's linear discriminant analysis (Fisher 1936; Rao 1973), as well as other, more advanced statistical methods like Classification and Regression Trees (CART; Breiman et al. 1984) and Support Vector Machines (SVM; Vapnik 1996, Wahba et al. 2000). Common to all these methods (when used for classification, i.e., CART and SVM are much more general) is the fact that the diagnostic category is the dependent variable in the statistical model, which is being predicted or described by the set of independent/predictor variables. As such, these methods are ill suited to address the question of whether a set of diagnostic categories makes sense; they take the categories as given, and two models that use two different sets of dependent categories are not directly comparable. However, they are very useful in understanding the patterns in symptom presentation between different diagnostic categories or subgroups, and in identifying which features distinguish between known subgroups and which do not.

On the other hand, unsupervised methods are directly applicable to the problem of subgroup identification and assessment. The construction of subtypes from a set of features is the purpose for which these methods were designed, and they provide a set of subgroups (or multiple sets, for some methods) that can be assessed for internal cohesion and external dissimilarity, or compared to a set of known subtypes. We describe here three commonly used clustering methods: *k*-means, mixture modeling, and hierarchical clustering.

k-Means

k-means (Lloyd 1957, MacQueen 1967, Hartigan and Wong 1979) is a popular clustering algorithm that assigns observations to clusters based on how close they are to cluster centers. The algorithm computes distances from each observa-

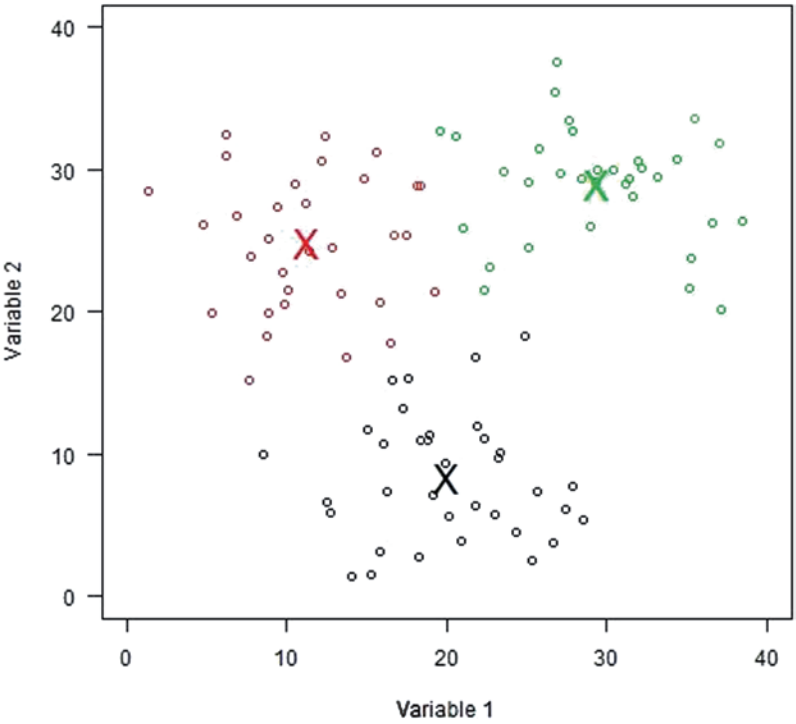


Fig. 2.1 *k*-means results using $k=3$ on a sample data set with 100 observations, with the clusters differentiated by *color*. The *X*'s indicate the centers of each cluster. (Reprinted from D. Campbell, Statistical Approaches to Subtyping appearing in *Encyclopedia of Autism Spectrum Disorders*, (F. Volkmar, editor), Fig. 2.1. With Kind permission of Springer Science + Business Media)

tion to each of *k* cluster centers using Euclidean distance. *k*-means then assigns each observation to its closest center, recalculates the *k* cluster means (hence the name), and repeats this back-and-forth process until the cluster assignments do not change anymore and the algorithm has "converged." An example of a set of clusters obtained via *k*-means with two variables, 100 data points, and $k=3$ clusters is shown in Fig. 2.1.

The *k*-means algorithm is computationally very fast, and the clusters it provides tend to be roughly comparable in size and shape. Because it uses Euclidean distance, it works best when all measurements are on the same scale, or else the variable with the largest range will dominate the distances between points; the data can, and usually should, be scaled to adjust for this. A significant limitation is that *k*-means is not designed to handle categorical measurements, because the distance between categorical labels, such as "Yes" and "No," is undefined. Like most clustering methods, *k*-means requires specification of the number of clusters, and making the wrong choice can yield poor clustering results.

Mixture Modeling

A broad set of clustering methods are collectively known as *mixture models* (Everitt and Hand 1981; McLachlan and Basford 1988). In these methods, a number of "latent" or unknown subgroups are assumed, and a probability distribution for each subgroup is specified in a statistical model. For example, the observations from each cluster may come from a multivariate Gaussian distribution, with unknown mean and standard deviation. Then, for each observation, the model calculates the probabilities of each observation belonging to each cluster. The discretized cluster assignment for each observation is determined by the cluster with the largest probability.

Mixture models have several advantages. First, unlike in *k*-means where clusters tend to be compact and circular in shape, the latent clusters found in a mixture model can take any arbitrary shape by defining the model appropriately. Second, there is a measure of uncertainty in cluster assignments, so an observation on the border between two cluster regions can have nonzero probability of belonging to either cluster. *k*-means, on the other hand, creates absolute cluster assignments—an observation either belongs to a given cluster or it does not, and each observation can only belong to one cluster at a time. The controlled uncertainty allowed in mixture modeling can be very helpful in understanding how well the clusters describe the data, and in identifying outliers that do not easily fit into any cluster.

Like the *k*-means algorithm, mixture models require you to specify the number of clusters. In addition, they also require that the distributions of each cluster be specified as well, which can yield a poor fit to the data if they are chosen incorrectly. While this can make the use of mixture models somewhat more complicated, the added complexity also allows clustering of more interesting and complex types of data, such as longitudinal data. By placing certain covariance, mixture modeling can find clusters in sets of curves; popular variants of mixture modeling that do this are latent growth curve analysis (Meredith and Tisak 1990; Muthen 1989; Willett and Sayer 1994) and latent trajectory analysis (Jones et al. 2001; Nagin and Tremblay 2001), and these methods have immediate applications for identifying subtypes in patterns of development of childhood with ASD.

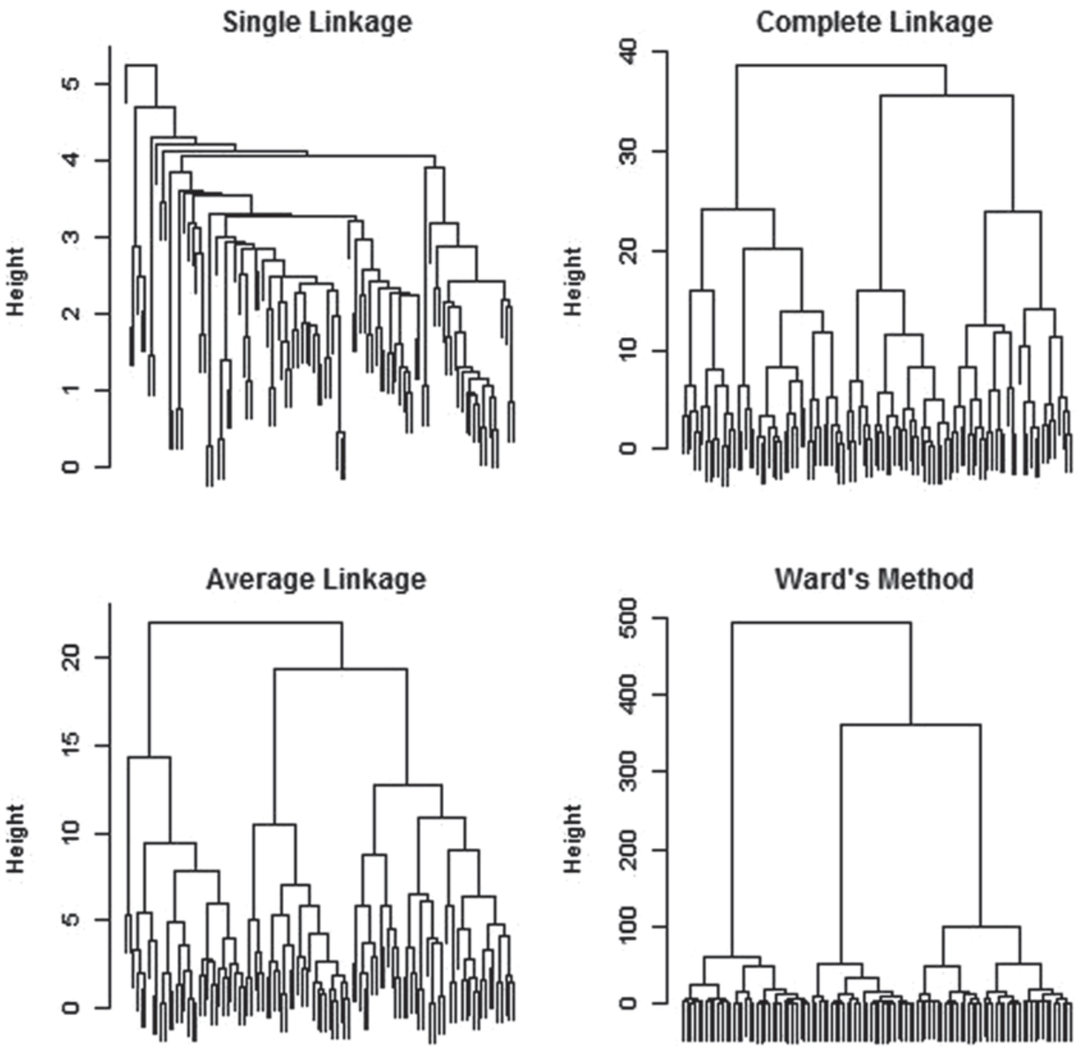
Hierarchical Clustering

Methods like *k*-means build their clusters by calculating the distance of each cluster to some cluster center. The cluster centers are not observations themselves, but rather arbitrary points. Alternatively, one could build clusters by grouping together observations that are close to each other but distant from others. This is the strategy employed by hierarchical clustering (Everitt 1974; Hartigan 1975).

The hierarchical clustering algorithm takes the set of all pairwise distances—distances from every observation to every other observation—and merges observations together into sets based on their proximity. The two closest observations get merged first, followed by the next two, and so on. The algorithm also needs one other piece of information, called the *linkage criterion,* which defines the distance from a set to other observations (or to other sets) given the pairwise distances. Using *single linkage* (McQuitty 1957; Sibson 1973), the distance from an observation to a set is the minimum distance to any of the members of the set, so two sets are close if they have a “single link” making them close. *Complete linkage* (Sorensen 1948; Everitt et al. 2001) instead uses the maximum distance to any member of the set, and two sets will be close under this criterion only if every pair of observations is close to each other. *Average linkage* (Sokal and Michener 1958; Murtagh 1984) attempts a compromise between single and complete linkage, and averages the minimum and the maximum distances. Ward’s method (Ward 1963, Székely and Rizzo 2005) takes a different approach, and combines the observations/sets together that give the smallest increase in variability by merging, so that each new cluster has the smallest possible variance.

Hierarchical clustering combines sets until all observations have been merged into a single, all-encompassing cluster. The end result is a *cluster tree* or *cluster dendrogram* made up of nested sets of clusters, where a pair of clusters is merged to give the partition with one fewer cluster. As such, it provides the cluster solution for all values of *k* simultaneously, although it is still up to the researcher to determine which value of *k* to select. Examples of cluster trees using four different linkage criteria are shown in Fig. 2.2.

Determining the “correct” number of clusters—and by extension, determining if multiple clusters are preferable to a single continuum—is one of the most difficult aspects of clustering. Because there is no known “true” grouping in the data (if there were, clustering analysis would not be necessary), there is no way to know the number of clusters with certainty, and instead alternative means of estimating the number of clusters and assessing the validity of a set of clusters must be used. Such methods can be internal, by looking at the statistical differences between clusters on the same variables used to make the clusters, or external, by relying on other variables not included in the clustering analysis to validate the clusters.



Single Linkage

Complete Linkage

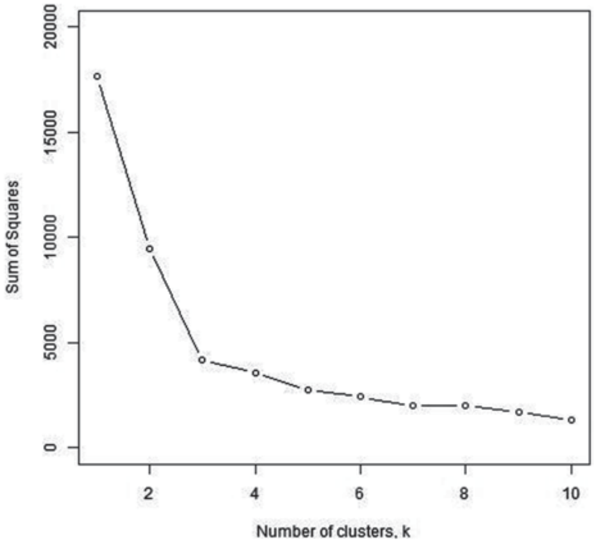
Average Linkage

Ward's Method

Fig. 2.2 The results of hierarchical clustering using four different linkage criteria on the same dataset used in Fig. 2.1. Notice that single linkage tends to produce many tiny clusters, while average linkage and Ward's method favor larger groups. While the overall tree structures are markedly different, on this particular dataset, complete linkage, average linkage, and Ward's method give nearly the same subgroupings if the tree is cut into three clusters. This is because the data strongly displays a three-cluster structure, as seen in Fig. 2.1. (Reprinted from D. Campbell, Statistical Approaches to Subtyping appearing in *Encyclopedia of Autism Spectrum Disorders*, (F. Volkmar, editor), Fig. 2.2. With Kind permission of Springer Science + Business Media)

In practice, choosing the number of subgroups using internal aspects of the cluster solution is commonly done by means of a variance plot, sometimes called a scree plot (Fig. 2.3). This plot graphs the number of clusters, *k,* on the *x*-axis, and a measure of variability or dispersion of the data on the *y*-axis, typically the within sum of squares summed over the *k* clusters. When $k=1$, the sum of squares gives the total amount of variability in the data; for larger values of *k,* the sum of squares will be smaller because the clusters explain some of this variability. The plot

Fig. 2.3 A scree plot showing the decreasing in sum of squares with increasing *k,* using *k*-means on the same data as in Fig. 2.1. Notice the *kink* at *k*=3, suggesting three subgroups in the data. (Reprinted from D. Campbell, Statistical Approaches to Subtyping appearing in *Encyclopedia of Autism Spectrum Disorders*, (F. Volkmar, editor), Fig. 2.3. With Kind permission of Springer Science + Business Media)



shows how much explanatory power (measured by a drop in variability) is gained by each additional cluster, with big drops in variability for the first few clusters, but much smaller drops as more and more clusters are added. Such a plot can suggest the best choice of *k* if it displays a "kink" or "elbow," where the marginal benefit of adding more clusters is relatively small and a more parsimonious clustering is preferable. Variants of this technique use different statistics for cluster dissimilarity than the sum of squares, like the Gap statistic (Tibshirani et al. 2001). A wide selection of methods for choosing the number of clusters in a dataset is compared in Milligan and Cooper (1985).

External information can also be useful in choosing the preferred number of clusters, as well as in assessing the meaning and interpretation of a given set of clusters once the number has been decided. A set of clusters can be validated though hypothesis testing, e.g., comparing differences in means between clusters using Student's *t*-test (for two clusters) or an F-test (for three or more clusters). Statistically significant differences in mean between some or all of the clusters on variables not used in the clustering algorithm can indicate clinically relevant differences between the subgroups. If some clusters do not exhibit statistically significant differences from each other, then they should perhaps be merged together to yield a more parsimonious subgroup structure. Care should be taken not to read too much into differences among the variables used to create the clusters; however, because the clustering procedure is designed to maximize differences on these variables, they cannot serve as outside sources of validation.

Another consideration is that a statistically significant difference in mean between groups does not necessarily imply that the data structure is better described by two clusters than by a continuous spectrum. In the extreme case of scores obtained by a single Gaussian distribution, with no evident bimodality in scores, a *t*-test comparing the means of scores above the average to those below will almost certainly reject the null hypothesis of equal mean. The fact that the means of the upper and lower halves of a distribution are unequal is not proof of bimodality in the distribution of scores, as this will likely be true regardless of the existence or nonexistence of cluster structure in the distribution. Thus, an accurate representation of the number of subgroups in a diagnostic category depends as much on the structural coherence and separation of subgroups as on the clinical differences between them.

Current Classification Systems and Issues of Autism Spectrum Disorders

The Pervasive Developmental Disorders of DSM-IV and ICD-10

Five distinct disorders were included under the category of pervasive developmental disorders in the DSM-IV (APA 1994), all of which have corresponding disorders defined in ICD-10 (WHO 1992). Except for a few minor differences, mainly in PDD-NOS/atypical autism, DSM-IV and ICD-10 have identical diagnostic criteria—this represented the first time that the American and international criteria were matched. The diagnostic criteria for each disorder were based on the best available clinical evidence, which, as stated previously, was based on the results of an extensive field trial (see Volkmar et al. 1994). The current diagnostic criteria for the five pervasive developmental disorders from ICD-10 are provided in Appendixes A–E. This section of the chapter provides an overview of these five disorders.

Autistic disorder/childhood autism Autistic disorder is characterized by impairment in each of the three core domains (e.g., social interaction, communication, and restricted repetitive behaviors). To receive a diagnosis of in DSM-IV of autistic disorder or in ICD-10 of childhood autism, the individual must exhibit (a) two of four social symptoms, (b) one of four communication symptoms, (c) one of four stereotyped or repetitive behaviors, (d) two additional symptoms from any domain, and (e) exhibit delays in social interaction, language as used for social communication, or symbolic or imaginative play by age three (see Appendix A). Individuals with autistic disorders who have intellectual disability are thought to have "classic autism" or "Kanner's autism" since these individuals most resemble the 11 cases first described by Kanner in 1943. However, autistic disorder is not limited to individuals with an intellectual disability; individuals with IQs above 70 are often referred to as having "high-functioning autism." As noted earlier, making distinctions between high-functioning autism and Asperger's disorder can, at times, be difficult, and the two diagnoses have, at times, been used interchangeably although each disorder has distinct and mutually exclusive diagnostic criteria (i.e., in order to meet diagnostic criteria of Asperger's disorder, one cannot have autistic disorder).

Asperger's syndrome The inclusion of Asperger's syndrome was the source of the greatest controversy in DSM-IV and ICD-10 (Volkmar and Klin 2005). Although debate continues regarding the best approach to defining AS (Rutter 2011), official recognition resulted in a dramatic increase in research (from approximately 75 papers prior to DSM-IV to more than 1,000 since its publication in 1994). Asperger's syndrome is characterized by typical language development through age three with deficits in social communication as well as the presence of circumscribed interests and/or restricted, repetitive, and stereotyped patterns of behavior. The diagnostic criteria (see Appendix B) include (a) at least two symptoms from the social interaction domain, (b) at least one symptom from the repetitive and stereotypic behavior domain, (c) relatively intact cognitive and communicative development through age three, and (d) gross impairment in everyday functioning. The period of communicative and cognitive development prior to age three during which typical milestones are reached is the primary difference between Asperger's syndrome and autistic disorder, and contributes to Asperger syndrome being, on average, diagnosed later in life than autistic disorder (Wiggins et al. 2006; Mandell et al. 2005; Noterdaeme et al. 2008; Williams et al. 2008). Although there has been a lack of agreement on a general diagnostic approach (see Volkmar and Klin 2005 for a review), data have shown important differences between Asperger's and higher-functioning autism, for example, in terms of neuropsychological profiles (Klin et al. 1995; Lincoln et al. 1998), comorbidity with other psychiatric disorders (Klin et al., in press), neuropsychological profiles, and family genetics (Volkmar and Klin 1998) and outcome (Szatmari et al. 2003).

PDD-NOS/atypical autism Both the DSM-IV and ICD-10 have subthreshold diagnoses for the pervasive developmental categories, PDD-NOS and atypical autism, respectively. PDD-NOS and atypical autism are diagnoses used when children have significant and pervasive deficits in social interaction but do not meet the diagnostic criteria for one of the other PDDs in the areas of communication, repetitive and stereotyped behavior, or, in the case of atypical autism, onset in early childhood. These diagnostic categories have the most ambiguously defined criteria (see in Appendix C), but the unifying feature between these diagnostic categories and the other PDD categories is the presence of severe social deficits. DSM-IV and ICD-10 take slightly different approaches to this category with ICD-10 providing the possibility for more fine-grained distinctions based on the way in which full criteria for autism or another of the explicitly defined PDDs are not met.

Childhood disintegrative disorder Childhood disintegrative disorder, also known as Heller's syndrome or disintegrative psychosis (see Heller 1908 and recent translation in Westphal et al. in press), is a extremely rare condition characterized by severe regression in more than one area of functioning (e.g., motor, social, language) after at least 2 years of meeting typical developmental milestones (Volkmar et al. 2005). The loss of skills generally occurs over the course of several months with developmental regression occurring prior to age ten, but typically by the age of five. Presentation of this disorder after regression is similar to autistic disorder, with children showing severe impairment in social communication skills, and restricted, repetitive, and stereotyped patterns of behavior.

Rett's syndrome Rett's syndrome (Rett 1966; van Acker et al. 2005) is a rare genetic condition found nearly exclusively in females characterized by typical development very early in life followed by a rapid decline in attainment of developmental milestones beginning in the second year of life. Early symptoms of Rett's syndrome such as language loss and reduced hand use may initially suggest a diagnosis of ASD, but Rett's syndrome can be distinguished from autistic disorder through the identification of decreasing rate of head growth, hand wringing stereotypies, and a progressive gait disturbance. Even though this syndrome is included as a PDD, although not without controversy (cf. Gillberg 1994; Rutter 1994), it has now been shown to be a clinically distinct genetic condition caused by a mutation in the methyl-CpG-binding protein 2 (MeCP2) gene at Xq28 (Amir et al. 1999); thus, its classification as a PDD in the future is in question. It is estimated that at least 1 of every 23,000 females have Rett's syndrome (van Acker et al. 2005).

Genetic Findings

Although first thought to be congenital in nature, there was much speculation beginning as early as the 1950s that autism might arise as a result of experience. However, longitudinal studies made it clear that autism was a strongly brain-based disorder with a very significant genetic component. For example, the first twin study (Folstein and Rutter 1977) showed a substantially increased risk for identical twins and an increased risk for fraternal twins and other siblings. Over time, a considerable body of work has been conducted, and it now seems clear that that multiple genes are likely to be involved (State 2010). There are also higher rates of certain psychiatric conditions including anxiety disorders and depression as well as higher rates of other problems including social problems (Rutter 2005). Progress in identifying potential mechanisms and subtypes is being made.

Broad Autism Phenotype

The broad autism phenotype refers to individuals who present a broader range of difficulties variously impacting social development, communication, and/or behavior, but who do not meet diagnostic criteria for an ASD (Losh et al.

2011; Volkmar and Klin 2005). Although discussed often as a unitary concept, definitions of the broad autism phenotype often differ greatly across research and clinical teams. Regardless of definition, these cases of atypical presentation of autism symptomology test the boundaries of the current classification system. A recent study has shown that individuals with broad autism phenotype who do not have an ASD show brain patterns that are more similar to individuals with ASD than those without (Wyk et al. 2010). Such findings have great potential for not only helping advance our understanding not only of the autism spectrum, but the etiology of mental disease and disorder more generally.

Autism in Infants and Young Children

Increased awareness and advances in early diagnosis have led to a change in the age at which autism is first diagnosed. In the 1980s and early 1990s, diagnosis of an ASD at age four was typical (Siegel et al. 1988), and a diagnosis of children under the age of three was somewhat novel and controversial. Beginning in the early twenty-first century, it has become more common for specialized diagnostic centers to see children in their first (Klin et al. 2004) or second years of life (Moore and Goodson 2003). Although diagnoses of young children appear quite stable, especially in terms of ASD vs. no ASD (Chawarska et al. 2007; Cox et al. 1999; Lord et al. 2006), the diagnosis of infants and very young children is a very complex process (Charman and Baird 2002; Cox et al. 1999; Stone et al. 1999). First, developmental changes occur very quickly in this age range and have great variability (Szatmari et al. 2002; Landa 2011). Behaviors typically seen in older cases (e.g., repetitive behaviors) are much less common in young children (Charman and Baird 2002; Cox et al. 1999; Lord 1995; Moore and Goodson 2003; Stone et al. 1999). Additionally, social abnormalities, which are the defining feature of ASDs, may not be present until social demands increase with the increasing complexity of social interactions in the preschool years. As reviewed above, there are many screening methods aimed at facilitated early diagnosis, and adaptation of standard screeners and diagnostic instruments for infants and toddlers has begun (e.g., Zwaigenbaum et al. 2009; Matson et al. 2009). Even with these advancements, clinicians must take great care in diagnosing autism in infants and toddlers given the complexities in detecting an ASD in young children (Chawarska et al. 2008; Landa 2011).

The Future of Autism Spectrum Disorder(s): DSM-5 and Beyond

The diagnostic classification of the five pervasive developmental disorders that has recently been replaced by DSV-5, had been in place for about 20 years. Over this time, research on these disorders has grown significantly, from several hundred papers in 1993 to over 2,400 papers last year (see Volkmar et al. 2011). This is a testament to the utility of the old system. However, concerns have continued as to whether the pervasive developmental disorders are distinct disorders, or if they are disorders lying on a continuum of one disorder. Given the lack of etiological findings and biomarkers reliably differentiating the different PDDs, at this time, this debate has not been settled. The new changes to the diagnostic criteria for ASD in DSM-5 have already fueled great debate in both popular press (e.g., Carey 2012, Jabr 2012a, 2012b) and scientific journals (Frazier et al. 2012; Lord and Jones 2012; McPartland et al. 2012; Matilla et al. 2011; Matson et al. 2012; Matson et al. in press; Worley and Matson 2012; Gibbs et al. in press). We conclude this chapter by providing an overview of the changes to the autism spectrum in DSM-5, followed by a discussion of possible implications that these changes might bring, concluding with thoughts about future directions for our field.

DSM-5 Conceptualization of Autism Spectrum Disorder

DSM-5 was published in May 2013 (APA, 2013). The new definition for the autism spectrum is termed ASD, which subsumes the diagnostic categories of autistic disorder, Asperger's disorder, PDD-NOS, and childhood disintegrative disorder. Hence, diagnostic subcategories for the individual PDDs cease to exist. The change of going from a category with five PDDs to a unitary category, i.e., ASD, has been met with much criticism and debate (Frazier et al. 2012; Lord and Jones 2012; McPartland et al. 2012; Matilla et al. 2011; Matson et al. 2012; Matson et al. in press; Worley and Matson 2012; Gibbs et al. in press). This change, according to the APA has likely been enacted in response to longstanding criticism of the reliability and robustness of DSM-IV-TR diagnostic subtypes and an emphasis on objectivity of diagnosis rather than clinical judgment. Many researchers and clinicians have been referring to autism as a spectrum disorder for many years now; thus, changing the name of the pervasive developmental disorders to ASD seems logical. Creating a diagnostic category encompassing the entire spectrum of individuals who have an ASD is sensible—*as long as the diagnostic threshold for the spectrum is defined in a way in which all individuals who have the disorder* (*i.e., autistic disorder, Asperger's disorder, PDD-NOS*) *are included and individuals who do not have the disorder are excluded.* An additional diagnostic category, social communication disorder (SCD) has also been created in DSM-5. It is unclear what effect, if any, this new diagnostic category will have on the composition of the autism spectrum. While SCD is mutually exclusive of DSM-5 ASD, there may be considerable overlap between it and the manner in which PDD-NOS was previously diagnosed.

The other significant change is moving from a triad of symptom domains to a dyad; the traditional triad of symptom domains (i.e., socialization, communication, and atypical behaviors) have been reduced to a dyad by combining the social and communication symptoms into a single domain (social communicative deficits). The second domain is termed "restricted repetitive behaviors" (RRB), and, for the first time, includes sensory abnormalities. In contrast to the current polythetic criteria (e.g., criteria in which different combinations of criteria can be combined to reach diagnostic threshold), DSM-5 requires individuals to meet all three social-communicative criteria simultaneously, akin to a monothetic approach (e.g., criteria in which all criteria are needed to meet diagnostic threshold). A polythetic approach is retained for the RRB criteria, requiring two of four symptoms. This shift from the polythetic approach of DSM-IV and ICD-10 to the combined monothetic and polythetic approach of DSM-5 creates a situation in which the possible combinations of symptoms for an autism diagnosis decreases from 2,027 distinct combinations for DSM-IV and ICD-10 to 11 for DSM-5 (McPartland et al. 2012). By changing the diagnostic requirements for ASD, it is likely that the composition of the autism spectrum will be different than it currently is today, which might be further complicated by the creation of SCD. This will no doubt complicate comparisons between research done prior to DSM-5 and service provision to cases that no longer simply fall into the new "autism spectrum" category.

Examinations of the Impact of DSM-5 ASD Criteria

There has been an oft-stated goal of the DSM-5 autism task force to make sure the new criteria do not exclude individuals who currently have the classification of one of the pervasive developmental disorders (less Rett's syndrome) from the new classification of ASD. However, multiple publications analyzing different sets of cases using different methodologies have suggested that many individuals who received a diagnosis according to DSM-IV or ICD-10 criteria might not meet the diagnostic threshold for DSM-5, especially for those individuals with higher cognitive abilities. McPartland et al. (2012) recently published analyses utilizing data collected during the DSM-IV field trial suggesting that among cognitively able individuals (those with IQ > 70), the portion of individuals that may no longer qualify for a diagnosis could be substantial. A majority of individuals clinically diagnosed with Asperger's disorder or PDD-NOS and approximately one-quarter of those with autistic disorder did not meet threshold on a diagnostic algorithm based on DSM-5 criteria (McPartland et al. 2012). The impact of the changes on individuals with ASD and intellectual disability were much less severe; however, 25 % did not meet the new diagnostic threshold. Similar results have now been shown across individuals of all ages by multiple research groups. Matilla et al. (2011), Worley and Matson (2012), and Gibbs et al. (in press) have both shown a similar percentage of children and adolescents currently diagnosed with a DSM-IV PDD would not meet DSM-5 criteria for ASD. Matson et al. (2012) showed 36.5 % of adults who had a developmental disability and ASD would not meet the new criteria. Finally, Matson et al. (in press) showed that nearly 50 % of infants meeting DSM-IV-TR criteria for one of the PDDs would not meet the new DSM-5 ASD criteria. Given these findings and the importance of this issue, it is likely that many more studies will continue to examine this controversy.

Conclusions and Future Directions

Definitive statements about the future composition of the autism spectrum cannot be made at this time. However, it is possible that the new DSM-V will essentially harken back to a more narrow definition of autism consistent with the more severe, pervasive difficulties seen in "classic Kanner's" autism. Such a change could have huge ramifications. In the USA, diagnostic labels, explicitly or implicitly, support selection of education and intervention services and are fundamentally integrated into the laws governing access to these supports. Major changes in clinical practice, such as altering who qualifies or fails to qualify for a diagnosis, can influence access to services. Thus, the classification systems (e.g., DSM, ICD) have important regulatory and policy implications (Rutter and Schopler 1992; Volkmar and Klin 2005). Unfortunately, the tendency to focus exclusively on the diagnosis as a label (rather than on the diagnostic process and comprehensive planning to address the individualized needs of each child as outlined in the Individuals with Disabilities Improvement Act) can impede good assessment and design of treatment plans (Volkmar and Klin 2005). The introduction of new diagnostic labels, such as Social Communication Disorder, may further complicate service eligibility and access. In addition to affecting service access, diagnostic labels provide a framework for organizing and interpreting research. The possibility that the term ASD could soon refer to a different group of individuals would prevent direct comparisons between participants in prior and future research and would limit generalization with past results.

Appendix A

ICD-10 Criteria for Childhood Autism (F84.0)

(A) Abnormal or impaired development is evident before the age of 3 years in at least one out of the following areas:

1. Receptive or expressive language as used in social communication
2. The development of selective social attachments or of reciprocal social interaction
3. Functional or symbolic play

(B) A total of at least six symptoms from (1), (2), and (3) must be present, with at least two from (1) and at least one from each of (2) and (3):

1. Qualitative abnormalities in reciprocal social interaction are manifest in at least two of the following areas:
    a. Failure adequately to use eye-to-eye gaze, facial expression, body posture, and gesture to regulate social interaction
    b. Failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions
    c. A lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behavior according to social context, or a weak integration of social, emotional, and communicative behaviors

   d. Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., a lack of showing, bringing, or pointing out to other people objects of interest to the individual)
2. Qualitative abnormalities in communication are manifest in at least one of the following areas:
   a. A delay in, or total lack of, development of spoken language that is *not* accompanied by an attempt to compensate through the use of gesture or mime as alternative modes of communication (often preceded by a lack of communicative babbling)
   b. Relative failure to initiate or sustain conversational interchange (at whatever level of language skills are present) in which there is reciprocal to-and-from responsiveness to the communications of the other person
   c. Stereotyped and repetitive use of language or idiosyncratic use of words or phrases
   d. Lack of varied spontaneous make-believe or (when young) social imitative play
3. Restricted, repetitive, and stereotyped patterns of behavior, interests and activities are manifest in at least one of the following areas:
   a. An encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature although not abnormal in their content or focus
   b. Apparently compulsive adherence to specific, nonfunctional, routines or rituals;
   c. Stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting, or complex whole body movements
   d. Preoccupations with part-objects or nonfunctional elements of play materials (such as their odor, the feel of their surface, or the noise or vibration that they generate)

(C) The clinical picture is not attributable to the other varieties of pervasive developmental disorder; specific developmental disorder of receptive language (F82.0) with secondary socio-emotional problems; reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70–F72) with some associated emotional or behavioral disorder; schizophrenia (F20.-) of unusually early onset; and Rett's syndrome (F82.4).

Source: *International Classification of Diseases: Diagnostic Criteria for Research,* tenth edition, by the World Health Organization, 1992, Geneva Switzerland: Author. Reprinted with permission

Appendix B

ICD-10 Criteria for Asperger's Syndrome (F84.5)

(A) There is no clinically significant general delay in spoken or receptive language or cognitive development. Diagnosis requires that single words should have developed by 2 years of age or earlier and that communicative phrases be used by 3 years of age or earlier. Self-help skills, adaptive behavior, and curiosity about the environment during the first 3 years should be at a level consistent with normal intellectual development. However, motor milestones may be somewhat delayed and motor clumsiness is usual (although not a necessary diagnostic feature). Isolated special skills, often related to abnormal preoccupations, are common, but are not required for diagnosis.

(B) There are qualitative abnormalities in reciprocal social interaction (criteria as for autism).

(C) The individual exhibits an unusually intense, circumscribed interest or restricted, repetitive, and stereotyped patterns of behavior, interests, and activities (criteria as for autism; however, it would be less usual for these to include either motor mannerisms or preoccupations with part-objects or nonfunctional elements of play materials).

(D) The disorder is not attributable to the other varieties of pervasive developmental disorder; simple schizophrenia (F20.6); schizotypal disorder (F21); obsessive-compulsive disorder (F42.-); anankastic personality disorder (F60.5);

reactive and disinhibited attachment disorders of childhood (F94.1 and F94.2, respectively).

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Appendix C

ICD-10 Criteria for Atypical Autism (F84.1)

(A) Abnormal or impaired development at or after the age of 3 years (criteria as for autism except for age of manifestation).

(B) There are qualitative abnormalities in reciprocal social interaction or in communication, or restricted, repetitive, and stereotyped patterns of behavior, interests, and activities (criteria as for autism except that it is not necessary to meet the criteria for number of areas of abnormality).

(C) The disorder does not meet the diagnostic criteria for autism (F84.0).

Autism may be atypical in either age of onset (F84.10) or symptomatology (F84.11); the two types are differentiated with a fifth character for research purposes. Syndromes that are atypical in both respects should be coded 84.12.

Atypicality in age of onset (F84.10)

(A) The disorder does not meet criterion A for autism (F84.0); that is, abnormal or impaired development is evident only at or after the age of 3 years.

(B) The disorder meets criteria B and C for autism (F84.0).

Atypicality in symptomatology (F84.11)

(A) The disorder meets criterion A for autism (F84.0); that is abnormal or impaired development is evident before the age of 3 years.

(B) There are qualitative abnormalities in reciprocal social interactions or in communication, or restricted, repetitive and stereotyped patterns of behavior, interests and activities (criteria as for autism except that it is not necessary to meet the criteria in terms of number of areas of abnormality).

(C) The disorder meets criterion C for autism (F84.0).

(D) The disorder does not fully meet criterion B for autism (F84.0).

Atypicality in both age of onset and symptomatology (F84.12)

(A) The disorder does not meet criterion A for autism (F84.0); that is abnormal or impaired development is evident only at or after the age of 3 years.

(B) There are qualitative abnormalities in reciprocal social interactions or in communication, or restricted, repetitive and stereotyped patterns of behavior, interests and activities (criteria as for autism except that it is not necessary to meet the criteria in terms of number of areas of abnormality).

(C) The disorder meets criterion C for autism (F84.0).

(D) The disorder does not fully meet criterion B for autism (F84.0).

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Appendix D

ICD-10 Criteria for Rett's syndrome (F84.2)

(A) There is an apparently normal prenatal and perinatal period *and* apparently normal psychomotor development through the first 5 months *and* normal head circumference at birth.

(B) There is deceleration of head growth between 5 months and 4 years *and* loss of acquired purposeful hand skills between 5 and 30 months of age that is associated with concurrent communication dysfunction *and* impaired social interactions and appearance of poorly coordinated/unstable gait and/or trunk movements.

(C) There is severe impairment of expressive and receptive language, together with severe psychomotor retardation.

(D) There are stereotyped midline hand movements (such as hand wringing or "hand-washing") with an onset at or after the time that purposeful hand movements are lost.

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Appendix E

ICD-10 Criteria for Other Childhood Disintegrative Disorder (F84.3)

(A) Development that is apparently normal up to the age of at least 2 years. The presence of normal age-appropriate skills in communication, social relationships, play, and adaptive behavior at age 2 years or later is required for diagnosis.

(B) There is a definite loss of previously acquired skills at about the time of onset of the disorder. The diagnosis requires a clinically significant loss of skills (not just a failure to use them in certain situations) in at least two out of the following areas:

1. Expressive or receptive language
2. Play
3. Social skills or adaptive behavior
4. Bowel or bladder control
5. Motor skills

(C) Qualitatively abnormal social functioning is manifest in at least two of the following areas:

1. Qualitative abnormalities in reciprocal social interaction (of the type defined for autism)
2. Qualitative abnormalities in communication (of the type defined for autism)
3. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities including motor stereotypies and mannerisms
4. A general loss of interest in objects and in the environment

(D) The disorder is not attributable to the other varieties of pervasive developmental disorder; acquired aphasia with epilepsy; selective mutism (F94.0); Rett's syndrome (F84.2), or schizophrenia (F20.-).

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Related Disorders

3

Joyce Suh and Deborah Fein

Keywords

Comorbidity · Related disorders · Intellectual disability autism · ADHD · Language Disorders

Autism spectrum disorders (ASDs), also referred to as pervasive developmental disorders (PDDs) in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association [APA] 2000) encompass a heterogeneous group of neurodevelopmental disorders with varying etiologies that have been behaviorally defined as having impairments in social communication, reciprocal social interaction, and repetitive, restricted behavior and interests (APA 2000). The spectrum includes autistic disorder, characterized by clear deficits in all three domains; Asperger's disorder, characterized by no significant language delay and average to above average cognitive functioning; and pervasive developmental disorder-not otherwise specified (PDD-NOS), characterized by significant social and communication impairments that do not meet full diagnostic criteria for autistic disorder (American Psychiatric Association 2000). According to current diagnostic criteria, symptoms must be present before 3 years of age. Current literature estimates the prevalence of ASDs to be 1:150, or 0.6–0.7 % (Rapin and Tuchman 2008), and even higher estimates of 1:110 have been published by the Centers for Disease Control and Prevention (CDC 2006). It should be noted that, at the time this volume is going to press, the American Psychiatric Association is publishing the DSM-V, which changes several aspects of the diagnostic criteria for autism (American Psychiatric Association 2013). However, this chapter discusses the longstanding previous diagnostic criteria, as these criteria have been the subject of the overwhelming majority of research.

ASD symptomatology overlaps with that of a range of disorders, including intellectual disability (ID), attention deficit hyperactivity disorder (ADHD), and language disorders and are frequently comorbid with these conditions as well as with psychiatric disorders such as oppositional defiant disorder (ODD), obsessive compulsive disorder (OCD), anxiety, depression, and schizophrenia (Tager-Flusberg and Dominick 2011). According to current diagnostic criteria, ID and schizophrenia can be diagnosed concurrently with ASD, whereas language impairment and attention symptoms are so prevalent in individuals with ASD that a diagnosis of ASD precludes a diagnosis of expressive language disorder, mixed receptive-expressive language disorder, or ADHD (APA 2000). There has, however, been considerable disagreement in the field

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as to whether these disorders should be able to be diagnosed concurrently with ASD (e.g., Sinzig et al. 2008).

ASDs have been conceptualized to have social dysfunction as part of their core symptomatology; in contrast, social deficits in other disorders, such as ID, ADHD, and language impairment (LI), are largely viewed as a secondary consequence of other core symptoms. However, there is sometimes so much overlap that it is difficult to differentially diagnose disorders. Furthermore, ID, ADHD, and language disorders are more frequently comorbid with ASD than would be expected by chance. The degree of overlapping symptomatology and frequency of comorbidity among these disorders suggests an examination of the nature of the relationship between ASD and these disorders. Although there are many disorders that are comorbid with ASD, this chapter will focus on three disorders that have been particularly difficult to differentiate from ASD: ID, ADHD, and language disorders. This chapter will discuss differential diagnoses and examine the current theories and research about the relationships of these disorders with ASD.

Autism and Intellectual Disability

Criteria for Intellectual Disability

ID (also referred to as "Mental Retardation" in the DSM-IV) is a developmental disorder characterized by significant deficits in cognitive functioning (usually an IQ<70) and deficits in two or more areas of adaptive functioning, which could include impairment in communication, socialization, or daily living skills such as dressing and feeding (APA 2000). In the DSM-IV, the diagnosis is further delineated by severity: mild mental retardation (IQ 50–55 to 70), moderate mental retardation (IQ 35–40 to 50–55), severe mental retardation (IQ 20–25 to 35–40) and profound mental retardation (IQ below 20 or 25: APA 2000). The prevalence of ID is estimated at 1–3% of the population (Leonard and Wen 2002). The etiology of ID varies and can include genetic disorders (e.g., Angelman syndrome, Down's syndrome, fragile X, Prader Willi, Rett syndrome, Williams syndrome, 22q11 deletion), environmental factors (fetal alcohol syndrome, environmental toxins, perinatal problems), or be of unknown origin (idiopathic). ID is frequently comorbid with other conditions, most prominently ASD and ADHD, but also psychiatric conditions such as depression, bipolar disorder, and schizophrenia (Bradley et al. 2004). A lower IQ increases the likelihood of a comorbid disorder (e.g., La Malfa et al. 2004).

There has been research in the ASD literature that has examined the prevalence of ID in individuals with ASD; conversely, there has been research in the ID literature about the prevalence of ASD in individuals with ID. The ID literature has found that between 17 and 40% of individuals with ID meet diagnostic criteria for ASD (Bryson et al. 2008; de Bildt et al. 2004; La Malfa, et al. 2004). This high prevalence of ASD in individuals with ID is significantly more than the 0.6–0.7% of ASD in the general population. Likewise, the ASD literature has found that many individuals with ASD meet criteria for an ID. Previous estimates of ID (defined as IQ of 70 or lower) in people with ASD used to be as high as 70–90% (Fombonne 2003). However, with better awareness of autism and the advent of more sensitive diagnostic measures, there have been more ASD diagnoses among individuals with average to above average cognitive abilities. In addition, earlier diagnosis and intensive treatment may lead to higher IQ at follow-up. Nevertheless, recent prevalence estimates of ID in individuals with ASD still range from 26 to 59% (Chakrabarti and Fombonne 2001; Fombonne 2003).

Overlapping Symptomatology

Intellectual disability in individuals with ASD ASD encompasses a range of cognitive ability, ranging from profound ID to superior cognitive performance. However, ID is significantly more common in ASD than in the general population. Furthermore, although the prevalence of ID in individuals across all ASDs ranges from 26 to 59%, the prevalence among individuals with autistic disorder (as opposed to a diagnosis of PDD-NOS or Asperger's) may be as high as 66–70 % (Chakrabarti and Fombonne 2001; Fombonne 2003). There is also a relationship between specific autism symptomatology and ID: in general, the people with the most severe autism symptomatology have the most severe ID. Furthermore, the impairments that are usually seen in autism, such as delayed or impaired language development (including difficulty in understanding and using language) and common comorbidities, such as attention problems and sensory issues, will make learning more difficult. Likewise, social impairments associated with autism could also delay or prevent learning, including lack of imitating, a foundational skill for learning, and a lack of motivation to please others or demonstrate mastery (Siegel 2010). All of these factors may lead to ID or the appearance of such a disability. However, individuals with ASDs can also have primary cognitive deficits that are independent of these social, language, and attention factors.

Autistic symptomatology with ASD in individuals with intellectual disabilities (ID) ID has greater symptom overlap than any other disorder (Wilkins and Matson 2009). Individuals with ID typically have a language and communication delay and socialization difficulties, two of the three main criteria to diagnose ASD (American Psychiatric Association 2000). The distinction between disorders is further complicated because 30–60 % of individuals with ID display repetitive behaviors, especially individuals with severe or profound ID (IQ<35; Bodfish et al. 1995, 2000; Goldman et al. 2009). Lord (1995) found that 8 % of 3-year-olds with ID displayed stereotypies. Bodfish et al. (1995) administered items about stereotyped and self-injurious behavior for a group of 210 adults with severe or profound ID and found that 61 % displayed stereotyped behavior, 40 % had compulsions, and 47 % displayed self-injurious behavior. However, while repetitive behaviors are present in both disorders, the frequency and severity of behaviors are more pronounced in autism than in ID without autism (Bodfish et al. 2000; Lord et al. 1995). Individuals who meet criteria for ID (with an IQ<70) are also more likely than individuals without ID to have echolalia, a common behavior in individuals with ASD. As would be predicted, individuals with more severe ID are more likely to meet criteria for an ASD than those with milder degrees of ID (La Malfa et al. 2004; Vig and Jedrysek 1999). Social and communication deficits are prevalent in this population because people with ID have more difficulty developing communication and socialization skills requiring higher cognitive abilities.

It is sometimes difficult to differentiate a severe ID from ASD. Measures such as the Autism Diagnostic Observation Scale (ADOS) and Autism Diagnostic Interview-Revised (ADI-R) can reliably differentiate children with non-autistic, mild and moderate ID from ASD, but have less reliability differentiating severe ID from ASD (de Bildt et al. 2004): while individuals with mild ID display social competency skills similar to typically developing individuals at about the same developmental level, individuals with severe ID may have severe social deficits (Ingram et al. 2007). Additionally, individuals with severe or profound ID are more likely to be nonverbal, so prototypically autistic features, such as echolalic or stereotyped use of language, and poor use of language for communication, will not be evident.

Differential Diagnosis

When diagnosing an individual with ASD and ID, the clinician must decide whether the behaviors indicate: ASD only, ID only (where the social and communication deficits are seen as resulting from low cognitive developmental levels rather than an underlying primary social deficit), or comorbid ASD and ID. In more straight forward cases, individuals with ASD and ID will be able to be differentiated by several main factors. First, individuals with ASD are more likely to have idiosyncratic language (e.g., stereotyped speech, scripted speech, neologisms, pronoun reversal) and atypical intense interests, such as an interest in vacuum cleaners or weather patterns. Furthermore, individuals with ASD have socialization scores on the Vineland Adaptive Behavior Scales (VABS; Sparrow et al. 1984) that are usually significantly below their cognitive scores, whereas individuals with ID will have socialization scores that are more consistent with their mental age (Liss et al. 2001; Hauck et al. 1995). This pattern will also be observed in other areas of adaptive behavior functioning, with the ID group displaying scores that may be low, but are generally consistent with their cognitive functioning, whereas the ASD group will be displaying adaptive functioning lower than would be predicted given their cognitive functioning. For example, a pattern that may be observed is that a child has greater language abilities (vocabulary, etc.) apparent in cognitive testing than is utilized day to day (i.e., Vineland Communication scores) because of a lack of motivation to utilize his or her language skills in daily life. Since Vineland Receptive Language items draw heavily on interest in and attention to language, this score can be particularly low in children with ASD .

ASD only versus comorbid ASD and ID In "straightforward" cases, an individual would meet criteria for a comorbid ID if he or she has scores lower than 70 on standardized cognitive tests such as the Wechsler Preschool and Primary Scale of Intelligence (WPPSI; Wechsler 2002), Wechsler Intelligence Scale for Children (WISC; Wechsler 2002), Wechsler Adult Intelligence Scale (WAIS; Wechsler 2008), or Stanford Binet (Roid 2003). This ASD + ID subgroup will have socialization skills and cognitive scores that are both low and significantly impact adaptive functioning. In contrast, individuals with only an ASD diagnosis will have cognitive scores above 70 and their adaptive functioning scores will likely be more impacted due to social factors rather than cognitive disability. However, many cases are not this straightforward. For example, many individuals with ASD have receptive language difficulties that will impact their ability to understand the directions for even nonverbal cognitive tests. Furthermore, they may have comorbid attention problems and have difficulty focusing on the test, or have behavioral issues and refuse to complete the test. Likewise, there will be many whose IQ scores will border 70, and in these cases the clinician will have to evaluate the degree to which the cognitive limitations are impacting adaptive functioning.

ID only versus ASD (either with or without comorbid ID) Many individuals with ID will have difficulty communicating and socializing, whether due to lack of understanding language or not developing socialization skills commensurate with their chronological age. Hauck et al. (1995) studied 33 children ages 7–14 years old who were attending special education programs: 18 had an autism diagnosis (mental age from 2.8 to 11.6 years); and 13 had an ID diagnosis (mental age from 2.7 to 8 years). The children were matched according to their nonverbal ability. Hauck and colleagues found although the children did not differ in Vineland Communication scores, vocabulary, or nonverbal skills, the Vineland Socialization scores were significantly lower for children with autism. Furthermore, the authors coded behavior in two contexts: during meals and during free play. They found that while children with autism initiated interaction with adults at the same frequency as children with ID, the children with autism displayed "lower level" interactions, such as asking for help, ritualized greetings, or touching. In contrast, children with ID participated in "higher level" behaviors, such as giving information to the teacher, imitating, and engaging in more reciprocally interactive behaviors. Additionally, children with autism were 1/3 *less* likely to initiate interaction with peers than children with ID: the authors postulated that interaction with peers may have more of a social quality, whereas interaction with adults may be more need based, resulting in children with ASDs engaging more in the latter activity than the former. Hauck and colleagues also found that children with autism initiated more in the structured setting (lunch) than in the nonstructured setting (free play), indicating that children with autism may display more social behaviour in structured settings.

Jackson et al. (2003) conducted another study on the same group of 33 children. The ASD and ID groups were matched on their verbal ability and chronological and mental age. Jackson and colleagues evaluated the children's response to initiation of social contact by adults and peers as well as their ability to sustain play interactions. The authors found that while neither the frequency of conversation nor frequency of response to adults differed between groups, children with autism were less likely to sustain interaction with peers (such as sustaining play activity). Furthermore, children with autism had more "no responses" (ignored social bids) and fewer overall positive responses (such as compliant, cooperative, or helping behavior) than their ID peers.

Therefore, while children with intellectual disabilities display communication and social behavior below what would be expected given their chronological age, their social behavior tends to be more consistent with their other abilities, whereas children with autism display more social difficulties than children with ID even when matched on mental ability. Furthermore, qualitative differences in social initiation and response are displayed in more social-emotional reciprocity, social engagement, and engagement with peers in the ID group, whereas social interactions in the ASD group is more adult oriented and interactions are more need based.

ID only versus comorbid ID and ASD Hepburn et al. (2008) studied 20 two-year-old children with Down's syndrome with a formal diagnosis of ID and evaluated autism symptoms by administering the Autism Diagnostic Observation Schedule-Generic (ADOS-G) and ADI-R and following up 2 years later to evaluate the stability of the diagnoses. They noted that children with Down's syndrome who did not meet criteria for an autism diagnosis nevertheless displayed behaviors associated with autism, including poor eye contact, restricted and idiosyncratic interests (such as an interest in parts of objects), and repetitive behaviors (such as rocking, hand-flapping). Hepburn and colleagues found that 3 out of 20 children (15 %) met the criteria for an ASD according to the ADOS. They also noted that while many children had difficulty with communication and play as well as restricted interests, they continued to display behaviors indicating social reciprocity. This included reciprocal social smiling, directing facial expression, joint attention, and attempts to imitate adults during the ADOS. However, none of the children met criteria for autism on the ADI-R, although the same three toddlers who met criteria for ASD on the ADOS met on the communication domain on the ADI-R. Clinically, two out of the three toddlers who met criteria on the ADOS were given an ASD diagnosis, whereas the third did not because she showed appropriate reciprocal social behaviors (e.g., effective modulation of eye contact, sharing affect, nonverbal reciprocity); rather her communication and socialization scores suffered because of her low mental age (<12 months). Therefore, communication and restricted and repetitive interests did not sufficiently differentiate the groups, although the clinical judgment about the presence or absence of reciprocal social interaction did. These findings are consistent with those of Jackson et al. (2003) and Hauck et al. (1995), described above, suggesting that quality of social engagement, rather than communication difficulty or repetitive behavior, is the best differentiator of children with ID who have and do not have an ASD.

Therefore, while individuals with ID may have difficulty communicating due to low level of receptive and expressive language, they are more likely to display reciprocal social behaviors and compensate through other social avenues of communication, such as gesture. However, if all levels of functioning are low, it will be difficult to differentiate whether socialization scores are meaningfully below other cognitive abilities.

Genetic Studies

ASD and ID occur more often together than they would by chance. Is there a genetic relationship between the two sets of disorders? Before commenting on this topic, it is important to note that ASD and ID are both heterogeneous disorders. Multiple genetic factors can contribute to both clinical phenomena; furthermore, the etiology for some individuals may not have a genetic component but result from environmental factors, such as perinatal insult, or a more general environmental factor disturbing neuronal and brain development.

There are some genetic disorders associated with ID where a comorbid ASD diagnosis is more likely than would occur in the general ID population. For example, 5–10% of individuals with Down's syndrome, 25–47% of individuals with fragile X syndrome, and 16–48% of individuals with tuberous sclerosis have a comorbid ASD diagnosis (review by Kaufman et al. 2010). Sikora et al. (2006) tested 14 children 3–16 years old with Smith-Lemil-Opitz Syndrome, a genetic form of ID, and found that approximately 75% met criteria for an ASD, with 50% of those diagnoses meeting criteria for autistic disorder. Furthermore, certain behaviors associated with ASD are more likely to be observed in certain syndromes. For instance, individuals with fragile X are more likely to avoid one's gaze or turn their head away in response to a greeting (Gillberg 2006). It is unclear, however why the ID and ASD diagnoses occur more often together in these conditions, whether it is due to overlapping symptomatology, genetic or neurologic vulnerability, or other factors. In their study of autism symptoms in toddlers with Down's syndrome, Hepburn et al. (2008) speculated whether individuals with Down' syndrome who meet criteria for ASD had "classic" autism, or whether there was a pattern of cognitive and communication difficulties in Down's syndrome that could negatively impact the development of communication skills and social reciprocity that would lead some children to meet criteria for an ASD as a secondary consequence of their Down's syndrome deficits.

Nevertheless research has found similar genetic regions or mechanisms impacted in ASD and ID. These include rare copy number variants (CNVs; deletions and duplications in the genome) that are present in both ASD and ID (Kaufman 2010). Areas that have been associated with both ASD and ID include *SYNGAP1*, *SHANK3,* and *IL1RAPL1* (Pinto et al. 2010). Pinto et al. (2010) speculated that with more research more genes associated with ID would be linked to ASD.

Hoekstra et al. (2009) found that there is little genetic overlap, at least for genes associated with "extreme" autism traits and genes for ID, but speculated that there may be genetic overlap with genes associated with communication abilities. Hoekstra et al. (2009) explored whether individuals with more severe autism symptoms were more likely to have a low IQ. They used a community sample and studied the 5% of individuals with the most severe autism traits and the 5% with the lowest IQs and found that the top 5% of the "most extreme" autism cases were 4.3 times more likely to perform in the bottom 5% on an IQ test. However, they found that the severity of autism was only modestly related to ID. Instead, most of the association between ID and ASD were due to communication items that were associated with ASD, suggesting that areas of genetic overlap between ASD and ID may be genes associated with communication abilities. Hoekstra and colleagues cited previous studies that showed that relatives of individuals with autism were more likely to have social and communication deficits in addition to lower IQs.

Theories About the Relationship Between ASD and Intellectual Disability

There are many ways to conceptualize the relationship between ASD and ID. On one hand, the "core" deficits from each disorder are likely to contribute and exacerbate the symptoms that are associated with the other disorder (i.e., lack of social motivation in ASD contributing to decreased motivation to learn, low cognitive ability in ID contributing to poor social skills). However, many individuals have ASD alone or ID alone; therefore, it is clear that symptoms of autism in many cases are not attributable to cognitive limitations, and vice versa. There are other factors at work. However, it is true that individuals with more severe ASD symptoms are more likely to have low cognitive functioning, and individuals with severe ID are more likely to have more ASD symptoms. What, then, is the relationship between ASD and ID?

Some attribute the high incidence of comorbidity to common genes that impact brain development interacting with the environment to produce a range of phenotypes, from ID to ASD, to a mix of other symptomatology (e.g., Morrow et al. 2008). Minshew and Meyer (2006) postulated that ID in ASD is a more severe expression of cognitive deficits that are seen in individuals with ASD who do not have ID. Siegel (2010) proposed that clinicians and researchers reconceptualize ASD as a type of learning disability, with different "autistic learning disabilities" (ALDs) and specific "autistic learning styles" (ALS). Other researchers have speculated that some individuals with a primary diagnosis of ID have autistic symptoms that have a different quality and etiology than "prototypical autism" (Hepburn et al. 2008).

Is there a difference between "ASD with comorbid ID" and "ID with comorbid ASD?" There has also been the question of how to diagnose individuals with such severe ID that it is difficult to determine whether ID or ASD is the primary impairment; however, although these questions may be important for genetic or other biological research, they are unlikely to dictate clinical decisions about assessment or treatment.

Conclusion

It is difficult to specify the relationship between ASD and ID, as both are behaviorally defined disorders with a range of etiologies. ID could result from various genetic disorders or environmental insults to the brain. Likewise, the behaviors attributed to ASD could arise from genetic or environmental factors as well as interactions between the two.

ASD encompass a wide range of ability and disability, from superior cognitive abilities to severe ID. Likewise, there is a range of social motivation and social behaviors seen in those with ID. There is behavioral overlap and frequent comorbidity between the two sets of conditions, and it is important to assess the cognitive functioning of people with ASD as well as the social and adaptive functioning of people with ID.

In many cases, it is important to differentiate whether an individual has a sole diagnosis of either ASD or ID, or comorbid ASD and ID, as this could inform treatment. For example, children with low IQ have poorer prognosis (Itzchak et al. 2008; Sutera et al. 2007), and individuals with comorbid ASD and ID are more likely to display stereotyped, repetitive, and self-injurious behavior than those with a sole ASD or ID diagnosis (Munson et al. 2008). Some studies suggest that a comorbid diagnosis increases the likelihood for additional psychopathology, including mood, anxiety, and sleep problems (Bradley et al. 2004), although other studies have found no differences in the number of psychiatric diagnoses in individuals with ID and those with comorbid autism and ID (Tsakanikos et al. 2006). However, as ASD and ID belong in a spectrum of ability and disability, there will be ambiguous cases, and in these cases it is most important to fully assess and be aware of the presenting behaviors, skills, and deficits, and treat them accordingly.

Autism and Attention Deficit Hyperactivity Disorder (ADHD)

Criteria for Attention Deficit Hyperactivity Disorder (ADHD)

ADHD is a developmental disorder characterized by inattention, hyperactivity, and impulsivity. There are three subtypes specified in the DSM-IV: Predominantly Inattentive Type, characterized by difficulty sustaining attention, organizing tasks, and paying attention; Predominantly Hyperactive-Impulsive Type, characterized by fidgeting, excessive physical activity, and difficulty inhibiting impulses; and Combined Type, characterized by inattention and hyperactivity and impulsivity symptoms (APA 2000). According to current diagnostic criteria, the onset of attention symptoms must be present before 7 years of age (APA 2000). The prevalence of ADHD ranges from 2 to 18 % of the population (Rowland et al. 2002). ADHD is frequently comorbid with other disorders, including ODD, Conduct Disorder (CD), ID, depression, anxiety, and ASD (Duric and Elgen 2011; Elia et al. 2009).

A study by Reiersen et al. (2007) found that 36 % of people diagnosed with ADHD (Combined Type) met the threshold for clinically significant autism symptoms as reported on the Social Responsiveness Scale (SRS). Moreover, 65–80 % of children with ADHD had significant difficulties with social interaction, conversation, and communication, core deficits seen in individuals with autism (e.g., Clark et al. 1999). Furthermore, attention problems are prevalent in individuals with ASD: an estimated 53–78 % of people diagnosed with ASD meet diagnostic criteria for ADHD, and attention problems are frequently present in individuals with ASD even though they may not meet diagnostic criteria for ADHD (Goldstein and Schwebach 2004; Lee and Ousley 2006; Sinzig et al. 2009). However, according to current diagnostic criteria in the DSM-IV, attention symptoms are subsumed under the ASD diagnosis, and a diagnosis of ASD precludes a diagnosis of ADHD (APA 2000), although it is likely that this prohibition will be eliminated in the next DSM. There continues to be debate about the nature of the relationship between ASD and ADHD, whether they should be regarded as comorbid disorders, whether they are discrete disorders with overlapping symptomatology, or disorders that lie on a continuum of symptomatology.

Overlapping Symptomatology and Differential Diagnosis

ASD Symptoms In Individuals with ADHD

Problems with Social Interaction

Shared symptomatology Mayes et al. (2012) administered the Checklist for Autism Spectrum Disorder (CASD) to informants concerning 847 children with autism and 158 children with ADHD ages 2–16 years old. The autism groups were differentiated by level of functioning (low-functioning autism (LFA) versus high-functioning autism (HFA)) and the ADHD groups were differentiated by ADHD subtype (ADHD combined (ADHD-C) and ADHD inattentive (ADHD-I)). Although the autism and ADHD groups were significantly different on all the items, the items with the most overlap involved problems with social interaction, which included difficulty making friends (100 and 96 %, for the LFA and HFA groups, respectively versus 26 and 13 % for the ADHD-C and ADHD-I groups, respectively), socially indiscriminate or insensitive behavior (75 and 74 % for the LFA and HFA groups, respectively; 39 and 24 % for the ADHD-C and ADHD-I groups, respectively) and problems with social skills (100 and 98 % for the LFA and HFA groups, respectively and 39 and 24 % for the ADHD-C and ADHD-I groups, respectively) .

Differential symptomatology Questions that differentiated the most strongly ASD and ADHD groups included: limited reciprocal social interaction (88 and 79 % for the LFA and HFA groups versus 5 and 2 % for the ADHD-C and ADHD-I groups) and the descriptor of seeming self-absorbed, or "in [his or her] own world" (90 and 83 % for the LFA and HFA groups versus 1 and 0 % for the ADHD-C and ADHD-I groups). A study by Hartley and Sikora (2009) corroborates some of these findings, but contradicts others. Autism symptomatology was evaluated in 55 children with HFA and 23 children diagnosed with ADHD by interviewing parents using DSM-IV-TR criteria for ASD. They found that the social relatedness domain differentiated the groups; however, while children with ASD had greater impairment in utilizing nonverbal social behaviors (directing facial expressions, use of gesture) and more difficulty developing friendships, parent endorsement of the quality of social and emotional reciprocity did not differentiate the groups. The former finding is consistent with Koyama et al. (2006), while the latter finding is consistent with Geurts et al. (2004). In addition, according to current diagnostic criteria, the onset of social deficits must have been evident before 3 years of age for a diagnosis of ASD, whereas the onset of symptomatology for ADHD must be before 7 years of age (APA 2000). Therefore, in general, individuals with ASDs are more likely to have difficulty in the area of social relatedness, utilize fewer nonverbal communication techniques, and tend to be described as more aloof than their ADHD peers; however, there is conflicting evidence on the ability to display social reciprocity, with some studies suggesting that individuals with ASD struggle more with displaying reciprocal social behaviors than their ADHD peers (Mayes et al. 2012; Koyoma et al. 2006), whereas others suggest that individuals with ASD and ADHD do not differ in the quality of their social and emotional reciprocity (Hartley and Sikora 2009; Geurts et al. 2004) .

Problems with Communication

Shared symptomatology Like individuals with ASD, individuals with ADHD are more likely to have deficits in pragmatic language, including difficulty beginning and sustaining a conversation and nonverbal communication (e.g., gestures, direction of facial expression; Clark et al. 1999). Furthermore, according to the study by Mayes et al. (2012), delayed speech, while significantly more common in children with ASD, is also more likely to be present in children with ADHD than in the general population (83 and 63 % for the LFA and HFA groups, respectively versus 20 and 9 % for the ADHD-C and ADHD-I groups, respectively).

Differential symptomatology However, there were factors that differentiated children with ASD and ADHD; children with autism were significantly more likely to display atypical speech or repetitive vocalizations (92 and 86 % for the LFA and HFA groups versus 4 and 0 % for the ADHD-C and ADHD-I groups). This is corroborated by the study by Hartley and Sikora (2009); they found that individuals with ASD were significantly more likely to display stereotyped and idiosyncratic language than their peers with ADHD. Furthermore, Mayes et al. (2012) found that no children with ADHD or typically developing controls were reported to have language regression, whereas 52 % of children with LFA and 20 % of children with HFA were reported to have lost some language after 1 year. Children with HFA were also significantly more limited in their play and imagination activities than their peers with ADHD (Hartley and Sikora 2009; Koyama et al. 2006).

Repetitive, Restricted Behaviors and Interests

Shared symptomatology, conflicting evidence There is conflicting evidence as to the degree that restricted, repetitive behaviors and interests are present in individuals with ADHD. Clark et al. (1999) found that 71 % of 49 children with ADHD displayed stereotyped hand or body movements, and some studies have found no significant difference in repetitive movements, nonfunctional routines and rituals, restricted interests, and preoccupation with parts of objects between individuals with ASD and individuals with ADHD (Hartley and Sikora 2009; Koyama et al. 2006). In contrast, in the study by Mayes et al. (2012), significantly more individuals with ASD were reported to have stereotypies (such as hand flapping and walking on their toes) than their ADHD peers (90 and 72 % for the LFA and HFA groups versus 6 and 4 % for the ADHD-C and ADHD-I groups).

Differential symptomatology Mayes et al. (2012) concluded that the presence or absence of restricted and repetitive behaviors was useful in differentiating ASD from ADHD, with higher levels of restricted and repetitive behavior and interests consistent with ASD. This included intense restricted interests (94 and 94 % for the LFA and HFA groups versus 1 and 0 % for the ADHD-C, and ADHD-I groups) and repetitive play such as lining up toys (87 and 65 % for the LFA and HFA groups versus 2 and 0 % for the ADHD-C and ADHD-I groups). Furthermore, no children with ADHD were characterized as showing an interest in repetitive movement such as spinning wheels and revolving fans and staring at the end credits of a television show or movie, whereas 51 % of children with LFA and 28 % of children with HFA displayed the behavior. In addition, no children with ADHD were characterized as having “special” skills that were incommensurate with their other abilities (sometimes called “savant” skills) which included characteristics that are associated with restricted repetitive interests, such as memorizing lines from movies and books displaying a comprehensive knowledge of a narrow subject, having an unusually good memory, reading early (before 3 years old) or having exceptional visual-spatial skills (such as a 2-year-old completing a 100-piece puzzle). However, it should be noted that 2 % of typically developing children were also reported to have an interest in objects with repetitive movement and 11 % were characterized as having "special abilities." In contrast, Hartley and Sikora (2009) concluded that the communication and social relatedness domains were better able to differentiate ASD and ADHD than restricted repetitive behaviors and interests. Future studies should examine whether there are differences between groups when severity and frequency of these behaviors, as well as qualitative features, are examined, rather than whether or not the behavior is present.

Problem Behavior

Children with ASD and children with ADHD are more likely to display problem behaviors than typically developing children. Both groups were more likely to be overreactive, get distressed by change, have meltdowns, and display aggressive behavior than typically developing controls (Mayes et al. 2012). There are also elevated rates of comorbid ODD diagnoses in both groups (Mayes et al. 2012).

ADHD Symptoms in Individuals with ASD

Studies have shown that it is difficult to differentiate ASD and ADHD by evaluating ADHD symptoms. Mayes et al. (2012) found that, according to parent report on the Pediatric Behavior Scale (PBS), the ASD groups displayed attention symptoms that were indistinguishable from the ADHD-C group. Likewise, other researchers have found similar attention profiles endorsed by individuals or families of children with ADHD and ASD, with significant attention symptoms endorsed by both groups (e.g., Frazier et al. 2001; Sinzig et al. 2009). Furthermore, the mean age of onset for ADHD symptoms (around 3–3.5 years old) was similar in the ASD and ADHD groups, suggesting that the course of ADHD symptom presentation is indistinguishable (Frazier et al. 2001). Sinzig et al. (2009) found that children with ASD fit the diagnostic criteria for the three ADHD subtypes. Parents of 83 children with ASD (ages 5–17) filled out the Diagnostic Checklist for ADHD, a checklist that covers the DSM-IV criteria for ADHD, and found that 53 % of the children met criteria for ADHD. More specifically, 46 % met criteria for the inattentive subtype, 22 % for the hyperactive/impulsive subtype, and 32 % for the combined subtype. The authors suggested that ASD and ADHD should be diagnosable as comorbid disorders.

Attentional processes in autism Studies have found very abnormal attentional processes in individuals with ASD. The ability to orient appropriately to novel stimuli or to selectively attend to particular sensory stimuli in the face of distraction may be deficient in individuals with autism: this inability to filter out incoming stimuli could lead to behaviors associated with inattention (Belmonte 2000; Posner and Rothbart 2007). Other studies suggest that individuals with autism are more likely to have difficulty shifting attention, such as disengaging from one target onto another target (Courchesne et al. 1994). Pascualvaca et al. (1998) administered the Wisconsin Card Sorting Task (WCST) and an alternative task called the Same-Different Computerized Task, and found that the children did not differ from controls on the latter task, although they performed worse than controls on the WCST. The authors concluded that children with autism have the ability to shift their attention, but have more difficulty doing so if they are already engaged in another activity. However, Goldstein et al. (2001) argue that the deficits in shifting attention may be explained by the cognitive flexibility required for some of the tasks (e.g., WCST), as these skills are deficient in some individuals with ASDs. Goldstein et al. (2001) also found that other differences in attentional processes were diminished when motor speed was used as a covariate. Nevertheless, Corbett and Constantine (2006) found that children with autism have deficits in visual and auditory attention. They administered the Integrated Visual and Auditory (IVA) Continuous

Performance Test (CPT) to 15 children with ASD, 15 with ADHD, and 15 typically developing children ages 7–12 and found that children with ASD and ADHD displayed deficits in auditory and visual attention. However, the ADHD group showed significantly greater impairment with auditory stimuli than the ASD group, whereas the ASD group showed significantly greater impairment with visual stimuli than the ADHD group. Furthermore, the ASD group displayed significantly greater difficulty with response control than the ADHD group, although both groups showed impairment relative to the control group. This suggests that children with ASD may have more difficulty with impulse control than children with ADHD. However, this study should be interpreted with caution due to the small sample size.

Individuals with ASD and individuals with ADHD both have difficulty sustaining attention on non-preferred tasks, but do well in sustaining attention on preferred activities. Garretsonm et al. (1990) investigated sustained attention to a non-language continuous performance test in children with ASD and controls matched for nonverbal mental age. They found that under certain circumstances (tangible reinforcement, first few minutes of the task, and slow rate of stimulus presentation), the children with ASD performed as well as their matched controls, but as time went on, their attention waned, and it was particularly impaired when social rather than tangible reinforcers were used and when rapid rate of presentation required more mental effort. In addition, they noted that while in the control group, repetitive (fidgety) behaviors were associated with poorer detection of targets, in ASD group, these behaviors were associated with better performance, suggesting that at least in some children, repetitive behaviors might be automatic and not detract from attention to stimuli.

There is also a tendency in individuals with autism to hyperfocus (Kinsbourne 2011). Some researchers suggest that this hyperfocusing may result from sensory overarousal or instability leading to a narrowing of attentional focus, which in turn leads to the restricted interests and behaviors that are observed in individuals with ASD (such as spinning the wheels of a toy car, staring at dust particles in the light, or an intense interest in toilets, vacuums, or other narrow subject matter; Baron-Cohen et al. 2009; Kinsbourne 1991; Kinsbourne 2011; Liss et al. 2006). while individuals with ASDs have an abnormally narrow focus and tend to concentrate on minute details rather then looking at the bigger picture, they also have difficulty inhibiting attention to irrelevant aspects of stimuli (review by Travers et al. 2011). Individuals with ASD are also less likely to attend to social stimuli and social cues, which may be due to a lack of social motivation or "social inattention" (Dawson et al. 2004; Garretson et al. 1990). Travers et al. (2011) suggested that this "social inattention" may result from general deficits in the ability to input attention and process attentional information: While individuals with ASDs also display a deficit in processing nonsocial information, the dynamic aspects of social interaction make this process even more difficult (for a review of attention in autism, consult Travers et al. 2011).

Executive Functioning Deficits in ASD and ADHD

Executive functioning, which involves organizing information, shifting attention, inhibiting potent responses, working memory, and cognitive flexibility, is impaired in both ASD and ADHD. Executive functioning is intricately tied to attention, as executive functioning involves the control and proper allocation of attention resources (review by Eigsti 2011; Semru-Clikeman et al. 2012). Although there are some conflicting studies, in general individuals with ASD: have more difficulty inhibiting responses, shifting set, and planning; have lower fluency and cognitive control; and perform worse on tasks involving working memory relative to their typically developing peers (review by Eigsti 2011). Two factors considered to be among the most severely impaired are cognitive flexibility and inhibition (review by Kelley 2011). Likewise, individuals with ADHD have difficulty inhibiting responses, planning, and have poorer working memory than their peers (Wilcutt et al. 2005). A study by Semru-Clikeman et al. (2012) compared the executive functioning profiles of children with Asperger's syndrome (AS), ADHD-combined type, and ADHD-inattentive type and found that children with AS were more likely to have difficulty with fluid reasoning, planning, behavioral regulation, and emotional control than their ADHD peers. They concluded that there may be differential executive functioning profiles in AS and ADHD. However, this should be interpreted with caution, as many studies with ASD are confounded by the differing levels of attention deficits that are frequently seen in ASD, as well as the wide range of functioning in individuals with ASD .

Executive functioning deficits are able to explain some of the common deficits that are seen in ASDs; for example, executive functioning has been implicated in the development of theory of mind (TOM) in young children (review by Eigsti 2011; Hughs and Ensor 2007). TOM is the ability to understand that others' thoughts, beliefs, and experiences are different from one's own, and is commonly reported to be impaired in individuals with autism (Beaumont and Newcombe 2006; Tager-Flusberg 1992). Likewise, executive functioning deficits could impact social functioning, both in people with ASD and with ADHD (for a review of executive functions in ASD, consult Eigsti 2011) .

Genetic and Neuroanatomy Studies

Genetic studies have also demonstrated that ASD and ADHD might be related: Individuals with autism are more likely than the general population to have family members with ADHD, and individuals with ADHD are more likely to have family members with ASD. Furthermore, studies have found shared candidate genes and similar regions of genetic linkage overlap (Rommelse et al. 2010). Some susceptibility sites in genes for ASD which include 2q, 15q, and 16p have been found to also be susceptibility regions for ADHD, (e.g., Rommelse et al. 2010). Other genes to explore include genes that regulate dopamine transport (such as the DAT1 gene) and genes that regulate the serotonin transporter gene, as dopamine dysregulation and downregulation of the serotonin transporter gene have been associated with both ASD and ADHD (Friedel et al. 2007; Gadow et al. 2008; Gillberg et al. 2009). However, there are a considerable number of genes that have been implicated in ASD that have not thus far been associated with ADHD, as well as genes associated with ADHD that have not been associated with ASD. Furthermore, some cases of ASD or ADHD may result from a few genes, or primarily environment, whereas other cases may relate more to polygenetic interactions, genetic loading, risk genes, epigenetic factors, and different gene–gene and gene–environment interactions.

Results bearing on possible shared anatomy in ASD and ADHD have been contradictory. This is exacerbated by the heterogeneous findings within each body of literature. However, there is some support for deficits in frontostriatal structures leading to deficits in executive functioning in ASD and ADHD (Gillberg et al. 2009), although this is a broad conclusion with little sensitivity or specificity. There has also been some support for a period of enlarged brain size early in life for a subset of children with ASD, whereas the brains of individuals with ADHD have been more likely to be smaller than control groups (Gillberg et al. 2009; for a review on anatomical findings in ASD, consult Herbert 2011).

Difficulty of Differential Diagnosis

Limitations of behavioral measures Researchers have acknowledged that current behavioral questionnaires are limited in their ability to identify the underlying reason for particular behaviors. For example, Sinzig et al. (2009) postulated that individuals with autism who display stereotyped behaviors score high on many of the inattention scales because they have difficulty attending to other stimuli when engaging in stereotyped behaviors. Furthermore, Clark et al. (1999) acknowledged that individuals with ADHD may score high on certain questions on autism checklists, such as "lack of awareness of feelings of others," and "hav[ing] difficulty forming relationships," not because of a lack of social motivation, but because of difficulty attending to the environment and to social cues, pointing to a different quality to a similar behavior. In addition, other social deficits in individuals with ADHD, such as inappropriate social behaviors, may be due to lack of inhibition and impulsivity (Reiersen et al. 2008). Likewise, the ADOS, considered the gold standard in autism diagnosis, also has some limitations when evaluating comorbid ASD symptomatology in children and adults with ADHD. For example, an individual with ADHD may have difficulty sustaining a conversation with the interviewer and go on tangents and speak out of turn, leading to poorer quality of conversation as well as a poorer quality of rapport. Likewise, someone with hyperactive symptoms may be restless and have difficulty paying attention to or participating in the activities, thus leading to inflated ASD symptom scores on activities that the individual did not complete (e.g., conversations that may examine the level of insight the individual may have into relationships). Individuals with ADHD are also more likely to have other comorbid disorders, such as ODD, CD, ID, and learning disabilities (LD) that could interfere with cognitive testing. For example, an individual with ADHD may not participate on a task because he/she is being oppositional, not because of a lack of social motivation. Furthermore, individuals with comorbid ID and ADHD have been found to be more likely to display more symptoms associated with ASD, including communication deficits, difficulty making friends, stereotypies, and obsessive interests (Mayes et al. 2012).

Fluidity of symptoms with age Furthermore, the ASD and ADHD symptom presentation may evolve and change with age. For example, hyperactivity and impulsivity symptoms in individuals with ADHD tend to decrease with age. Studies of individuals with ASD have been conflicting: some show ADHD symptoms decrease with age whereas others show ADHS symptoms increase with age (Gillberg et al. 2009). To further complicate the clinical picture, Gilberg et al. (2009) describe a subset of children who initially presented with ADHD but later met criteria for an ASD. There have also been cases of children with a formerly prototypical ASD symptom presentation whose symptoms evolved into a prototypical ADHD presentation (Fein et al. 2005). Fein et al. (2005) proposed five hypotheses to account for this observation. These hypotheses are linked to the current theories about the relationship between ASD and ADHD.

Theories About the Relationship Between ASD and ADHD

The following are the hypotheses proposed by Fein et al. (2005) to account for how children with clear ASD diagnoses lost their ASD diagnosis and later met clear-cut criteria for ADHD :

Hypothesis I Attention problems are *part of the autism phenotype*; as the more central autism symptoms subsided, the attention problems, which are harder to remediate, remained (as also suggested by Sinzig et al. 2009).

Hypothesis II ASD-ADHD is a *specific subtype of ASD* where individuals have more marked attention symptoms; as the central social symptoms subsided, the attention problems, which are harder to remediate, remained (as also suggested by Sinzig et al. 2009).

Hypothesis III ASD and ADHD are *comorbid*; as the ASD features subsided, the ADHD features became more prominent (as suggested by Goldstein and Schwebach 2004; Sinzig et al. 2009).

Hypothesis IV There is a *severe subtype of ADHD* that presents as ASD; as the ADHD symptoms decreased, it evolved into a more conventional ADHD presentation (as suggested by Reiersen et al. 2008).

Hypothesis V ASD and ADHD belong in the same *spectrum of impaired attention and arousal,* where the more impaired arousal presents as ASD and the less impaired arousal presents as ADHD; as the arousal and attention symptoms improved, it evolved into a more conventional

ADHD presentation (as suggested by Kinsbourne 1991, 2011; Liss et al. 2006).

Therefore, there are several ways ASD and ADHD could be related: attention problems are part of the autism phenotype; significant attention problems in ASD are a specific subtype of ASD; ASD and ADHD are comorbid; significant social problems in ADHD are a specific subtype of ADHD; and ASD and ADHD are part of a spectrum of impaired attention and arousal. Furthermore, there are situations where ASD-type social behaviors are better explained as originating from core ADHD symptoms (e.g., problems with social communication due to impulsivity rather than lack of social motivation), and ADHD behaviors that are better explained as originating from core ASD symptoms (e.g., inattention to the environment due to lack of social motivation to respond to the environment) .

Conclusion

It is likely that all the preceding relationships are possible (e.g., some individuals' symptoms are better explained as an ASD subtype with significant ADHD symptoms, whereas others have comorbid ASD and ADHD, etc.); however, currently there is no good way to determine which model best explains the etiology of a particular case. Parsing out the precise relationship between ASD and ADHD remains a challenging endeavor, as ASD and ADHD each represent a heterogeneous range of disorders with presumably heterogeneous etiologies (Rommelse et al. 2010).

However, what is known is that there is considerable overlap in symptomatology. Therefore, it is important to assess ADHD symptoms in individuals with ASD and to assess ASD symptoms in individuals with ADHD, especially since it is not uncommon for ASD to initially be misdiagnosed as ADHD, especially when social symptoms are not evaluated (Hartley and Sikora 2009).

Although research is mixed as to which factors best differentiate ASD from ADHD, research generally shows that it is easier to differentiate the two disorders by presence or absence of ASD symptomatology (which include the lack of reciprocal social engagement and joint attention, idiosyncratic and stereotyped language, and decreased utilization of nonverbal communication) than ADHD symptomatology. Furthermore, clinicians must keep in mind that similar behaviors may have different etiologies, although this would not necessarily entail different treatment approaches.

Autism and Language Disorders

Criteria for Communication Disorders/ Language Impairment (LI)

Current diagnoses on the DSM-IV for communication disorders include expressive language disorder and mixed receptive/expressive language disorder (APA 2000). Expressive language disorder is characterized by expressive language performance that is significantly below nonverbal and receptive language scores, whereas mixed receptive/expressive language disorder is characterized by receptive and expressive language performance significantly below nonverbal abilities. Currently, a diagnosis of either disorder precludes an ASD diagnosis. However, the DSM-V proposes a new diagnosis of language impairment (LI) that is characterized by language abilities that are significantly below age expectations, getting away from the discrepancy criteria that have been much criticized. Proposed subcategories include specific language impairment (SLI), social communication disorder, late language emergence, and selective mutism (dsm5.org). According to these criteria, an ASD diagnosis could be diagnosed in conjunction with an LI diagnosis. Research studies have been inconsistent in their use of language terminology, such as "developmental language delay" (DLD) and "specific language impairment" (SLI). For the purposes of this chapter, we will use the term SLI unless the study references specific language subtypes.

There has been considerable debate as to the relationship between ASD and other language disorders, as communication impairment is a significant component of the ASD diagnosis and most individuals with autism acquire language late (e.g., Bishop 2003). The level of language impairment varies widely in ASD, from an estimated 20–50 % with no functional speech (Bryson et al. 1988; Lord et al. 2004) to those with Asperger's disorder, who have average to above average structural language functioning but impaired pragmatic language abilities (Rapin 2007). SLI is characterized by delayed language not attributable to other factors, such as ID, hearing loss, or physical limitation.

In language disorders, there could be impairment in structural language functioning, such as grammar (syntax, morphology) and phonology, and impairment in functional language functioning, such as semantics (the meaning of language) and pragmatics (the conversational use of language). In high-functioning ASDs, there are language deficits that are more likely to not be present or to resolve, including deficits in phonetics, morphology, syntax, and concrete vocabulary. Semantic and pragmatic abilities are more persistent, and by definition people with ASD have pragmatic language deficits (review by Kelley 2011). How do these factors cluster together in children with language disability?

Types of Language Disability in Children with ASD and Children with Language Disorders Allen and Rapin identified three main clusters of language disability in children with language disorders, including children with ASD: (1) mixed receptive/expressive or global disorders, (2) higher-order processing language disorders; and (3) expressive phonology with or without grammar disorders (Rapin et al. 2009). The two former categories were seen both in children with only language disorders and in children with ASDs, whereas the latter was observed mostly in children with only language disorders. Mixed receptive/expressive or global disorders were the most severe, with communication impairment ranging from no comprehension of speech to impaired comprehension and deficits in phonology, grammar, semantics, and sometimes pragmatics; higher order processing language disorders generally consisted of comprehension, expression, semantic, and pragmatic difficulties with largely intact phonology and grammar; whereas expressive phonology with or without grammar disorders could include difficulty articulating speech, word-finding problems, or a poor vocabulary, with intact comprehension and pragmatics as well as a motivation to communicate.

ASD and SLI have overlapping symptomatology: some individuals with ASD display structural language deficits that parallel the deficits seen in SLI, including difficulty with nonword repetition (Kjelgard and Tager-Flusberg 2001), and some individuals with language impairment display pragmatic language deficits. Considering some common patterns of language disability in children with SLI and children with ASD and overlapping symptomatology, there has been considerable debate over the nature of the relationship between language disorders and ASD, including whether language disorders should be able to be diagnosed in individuals with ASD or whether language disability is subsumed under the ASD diagnosis. There has also been discussion about the boundary between language disorders and ASDs, including whether they lie on a spectrum of disability or are distinct disorders with different etiologies. These questions remain largely without definitive answers.

Overlapping Symptomatology and Differential Diagnosis

Differential diagnosis One of the main distinctions between SLI and ASD is that while children with language disability attempt to compensate for language difficulties by utilizing nonverbal communication, individuals with ASD are less likely to do so. For example, a child with language disability will utilize facial expressions and gestures such as pointing to communicate. In contrast, modulation and direction of facial expressions and effective use of gestures to communicate are considered key deficits in ASD (although we must keep in mind the heterogeneous nature of symptom expression in ASD and that not all children may display these deficits). Furthermore, social difficulties in individuals with language disability are considered secondary to the language deficits, whereas these social difficulties and lack of social motivation are considered a core part of the autism symptomatology. Another distinction has been the idiosyncratic and stereotyped language utilized by individuals with autism. This includes stereotyped speech, such as the repetition of phrases and lines from movies, neologisms (made-up words), echolalia (repeating what another person says right after he or she says it), atypical prosody (i.e., monotone, speaking too loudly or too softly) and pronoun reversal (i.e., "saying 'you' instead of 'I'"). Furthermore, people with ASD display repetitive, stereotyped behaviors or interests, whereas this is not observed in many individuals with SLI. Finally, one of the main distinctions between ASDs and SLI is the nearly universal pragmatic language deficits in individuals with autism. This includes having difficulty with the social conventions of language, such as knowing how to begin, sustain, and end a conversation; physical distance and tone of voice; *word selection, or having difficulty understanding that conversation is a social exchange where there is give and take and sharing of ideas and experiences*; Many individuals with autism also engage in one-sided conversations where they talk about their own interests rather than engaging in learning about others' interests or gauging others' reactions. However, case studies and research have found a more complicated clinical picture, where there are some who do not neatly fit into these categorical distinctions.

Difficulty of Differential Diagnosis: Overlapping Symptomatology, Change in Clinical Presentation of Disorders Bartak et al. (1975) conducted a study of children with ASD and "specific developmental receptive language disorder" and, although most of the cases were clear-cut, there were five borderline cases of children who had symptoms of both ASD and language impairment who could not be clearly distinguished as belonging to one group over another. Furthermore, Rapin and Allen (1983) identified a group of children with language impairment who displayed significant pragmatic language difficulties, although they did not meet criteria for an autism diagnosis. They identified this group as having "semantic pragmatic language deficits." Rapin and Allen stated that what especially differentiated this group from individuals with ASD was that while this group displayed some difficulties with the social use and understanding of language, they were motivated to engage in social interaction. Other researchers have also identified this subgroup, and these individuals have since been characterized as having pragmatic language impairment (PLI), considered a subtype of SLI (e.g., Bishop and Norbury 2002).

However, the specific criteria for PLI are unclear. Norbury and Bishop (2002) tried to define this subgroup for their study, which compared language characteristics and story recall in children with SLI, PLI, or an ASD. The authors defined the PLI group as receiving a score of 132 or below on the Children's Communication Checklist (CCC; indicating pragmatic language difficulties) and not meeting full criteria for autism on *both* the Social Communication Questionnaire (SCQ) and the ADOS. In contrast, the HFA group had to meet criteria on both autism measures, whereas the SLI group was open-atonalized as receiving a score greater than 132 on the CCC (indicating sufficient pragmatic language skills) and not meeting criteria on either of the autism measures. Therefore, almost by definition this PLI group lay on a spectrum that could be considered continuous with the ASD and SLI groups. As would be expected, 25 % of their PLI group consisted of children who had previously received diagnoses of "ASD", "atypical autism," or been described as having "autistic features," or a "complex language disorder." Therefore, there does not seem to be a general consensus or consistency in how to diagnose individuals with pragmatic language deficits. Although there is no consensus on this issue, Norbury and Bishop concluded that the term "pragmatic language impairment" (PLI) should be a descriptive (rather than a categorical) term that could apply to individuals with ASDs, language disorders, or individuals displaying symptomatology "somewhere between the two."

In addition, the presentation of ASD and SLI could change across the lifespan and the boundary between the two disorders become less distinct, even for people with clear-cut ASD or SLI diagnoses earlier in life. Bartak et al. (1975) studied boys ages 5–10 years old who were clearly diagnosed with either autism or “specific developmental receptive language disorder.” The boys were matched for expressive language level and nonverbal IQ (NVIQ). At this point, the autism group displayed significantly more impairments in regards to imaginative play, stereotyped behaviors, social skills, communication (such as more “deviant” language), language comprehension, and adaptive use of language. A follow-up study was conducted 2–3 years later, which found that while the two groups were still clearly distinguishable, a significant subset of children with language impairment displayed significant behavior problems and had difficulties in their peer relationships (Cantwell et al. 1989). Another follow-up at 21–28 years of age found that the symptomatology between the two groups continued to converge (Howlin et al. 2000; Mawhood et al. 2000). Howlin et al. (2000) found that while stereotyped behavior, social behavior, and adaptive behavior were more impaired in young adults with autism, a significant subset of individuals with language disability showed similar impairment: many had few close friends, displayed abnormalities in social interaction, did not have jobs, and lived with their parents. According to measures of social competence (ADI-R; socialization subscale of the VABS; and informant version of the Socio-Emotional Functioning Interview (SEF-I)), 10 % of adults with language disability had “severe social difficulties,” while another 65 % had “moderate social problems.” Furthermore, some adults initially characterized in the language-impaired group had unusual repetitive or restricted behaviors or interests: five were characterized as “unusually routinized,” four displayed “unusually” negative reactions to change; five had interests that took an “unusual” amount of time, and two had unusual preoccupations that took a significant amount of time and interfered with daily functioning (one had a significant interest in buses and another in racing pigeons). Furthermore, 55 % of the language-impaired group displayed an “intermediate” level of problem behaviors on the Maladaptive subscale of the VABS. In contrast, while the language abilities in the autism group on the whole were more impaired than the language disability group, the autism group made more gains, and it became more difficult to differentiate the two groups. Mawhood et al. (2000) conducted a discriminant functional analysis, and while this was able to distinguish the ASD and language-impaired groups in prior studies (Bartak et al. 1975; Cantwell et al. 1989), the distinction was not as clear by adulthood: for example, there were some who, according to the discriminant functional analysis now belonged to the other group.

Limitations of Behavioral Measures

Bishop and Norbury (2002) administered the ADOS and the ADI-R (a parent report measure) and/or the SCQ to children with language impairment and found that although there was good agreement between the two parent report measures, the agreement between the ADOS and a parent report measure was poor: out of 45 children, there was disagreement about the classification of 26 children: For example, out of 28 children characterized as “unaffected” on the ADOS, 15 met criteria for an autism or PDD-NOS diagnosis on parent report; likewise, out of 19 children characterized as “unaffected” on the ADI-R or SCQ, six met criteria for autism or PDD-NOS on the ADOS. This emphasizes the importance of clinical judgment as well as how difficult it can be to distinguish these disorders. The authors speculated that this also shows how the symptoms may have changed with age, as some children who met criteria for an ASD at 4–5 years old (according to parent report) no longer met criteria at 6–9 years old.

Genetic Studies

Studies suggest a genetic relationship between autism and language impairment: siblings of children with SLI are more likely than the general population to display autism symptomatology (Hafeman and Tomblin 1999), and family members of children with autism are more likely to have a history of language delay or other speech or language disorders (Fombonne et al. 1997; Le Couteur et al. 1996). Landa et al. (1991) examined the narratives of parents of children with autism and found that their narratives were less complex and less coherent than a control group of parents with typically developing children. Furthermore, studies show that genes linked with language impairment are also associated with autism, such as *CNTNAP2* polymorphisms, which have been found in children with SLI as well as children with autism with language delays (Vernes et al. 2008). Warburton et al. (2000) also found an area on chromosome band 7q31 that was implicated in autism and developmental language disorders and noted that this region of chromosome 7 shows strong linkage in multiplex families with autism.

Other researchers have suggested that the language deficits seen in SLI and in ASD have different etiology (e.g., Whitehouse et al. 2007). Whitehouse et al. (2007) compared the social and language abilities of parents of children with SLI and parents of children with ASD to determine whether there were shared language and social characteristics. The parents of children with autism performed significantly better than parents of children with SLI on language tests but displayed significantly more pragmatic difficulties. More specifically, a significant subset of parents with children with SLI displayed some difficulty on tasks of nonword repetition, a characteristic considered to have a genetic component (deficits in nonword repetition have been linked to a locus on 16q in SLI), whereas only one parent in the ASD group displayed the same difficulty. Whitehouse and colleagues concluded that the language deficits observed in individuals with ASD have a different etiology from those observed in individuals with SLI. However, there are limitations to this study. Only 9 out of 30 children with ASD had difficulty with nonword repetition; therefore, it would be less likely for the parents of children without these deficits to display problems in phonological processing. Furthermore, Whitehouse and colleagues assumed that even if a child did have a gene that contributed to deficits in nonword processing, that this would have been passed down by the parents; that is, they do not consider the possibility of de novo mutations. However, Bishop et al. (2004) found similar results: they studied 80 probands with autism and their parents and siblings and did not find a greater than expected incidence of phonological processing deficits. These findings support the theory that ASD and SLI may share certain phenotypic characteristics, but those characteristics may derive from separate factors—similar behaviors do not necessarily suggest a shared etiology.

Theories About the Relationship Between ASD and Language Disorders

There are many other theories about the relationship between ASD and language disorders. One is that there are no clear boundaries between the disorders and they lie on a continuum of symptomatology (Bishop and Norbury 2002; Botting 2002). Bishop (2000) proposed that researchers and clinicians use a dimensional approach (rather than a categorical approach) to understand language disorders. For example, SLI could be conceptualized as being located on the mild end of the spectrum, with PLI in the middle and ASD in the more severe end of the spectrum. However, Bishop (2003) emphasized the complexity of the relationship, as there is not a clear linear relationship between ASD and SLI. For example, individuals with SLI display structural language deficits, whereas there are many individuals with ASD who do not. ASD and SLI could also be conceptualized as distinct disorders that have overlapping symptomatology (e.g., Lindgren et al. 2009; Whitehouse et al. 2007). It has also been proposed that there may be a subset of individuals with ASD who have SLI and that a comorbid diagnoses be permitted in the DSM (dsm5.org; Kjelgaard and Tager-Flusberg 2001). ASD could also be the result of the accumulation of certain risk genes, such as social interaction and communication, which lead to certain deficits, such as deficits in imitation or difficulty paying attention, that could lead to phenotypes similar to those seen in SLI (Bishop 2003). Another theory is that there are separate genotypes for different areas of language functioning: impaired language structure, abnormal language use, impairment in social interaction, and restricted behaviors. "SLI" manifests when only the "impaired language genotype" is activated, whereas in ASD, all areas are affected (Bishop 2003). Additionally, there may be genetic risk factors that tend to compromise brain development, and through interaction with the environment diverge and lead to a phenotypic manifestation more similar to SLI or ASD (Bishop 2003).

Kelley (2011) proposed three theories to explain why people with ASD have language deficits: the Central-Coherence Theory, TOM, and the Executive-Dysfunction Theory. The Central Coherence Theory posits that people with ASD have difficulty with language because they have a harder time looking at the bigger picture; therefore, although while people with ASDs with intact language skills tend to be good at the detail and rule-governed aspects of language, such as grammar, they have difficulty understanding the broader aspects of language, such as using language for inference or reasoning. The TOM posits that children with ASD have more difficulty developing language skills because of deficits in understanding other people's points of view. For example, children with ASD who lack joint attention will be less equipped to learn language from other people. Finally, the Executive-Dysfunction Theory posits that dysfunction in the ability to switch attention and have cognitive flexibility impedes the development of TOM and also makes it harder to learn language because of difficulty following along in conversations. Therefore, there may be underlying deficits in ASD that make it harder for people to learn and develop language skills.

Language Disability in ASD: Subsumed Under the ASD Diagnosis or Comorbid Condition?

Although there has been much debate about this, the research by Rapin et al. (2009) that looked at clusters of language disability in children with ASDs found that the clusters found in children with ASDs roughly corresponded to the ones seen in children with language disorders. The first main group (Clusters 1 and 2), consisting of children with low phonology, corresponded to mixed receptive/expressive global disorders, whereas the second main group (Clusters 3 and 4), consisting of children with low average to above average phonology, corresponded to higher-order language disorders. More specifically, Cluster 1 (low phonology, low comprehension) corresponded to phonologic-syntactic disorder. Cluster 2 (low phonology, near average comprehension) did not map onto a clinical syndrome, although the author's conjectured that this may have been due to improved language ability with age. Cluster 3 (average phonology, low to low average comprehension) corresponded to the higher order processing deficit type, although, possibly due to the greater age in this sample than the original Rapin-Allen samples (school age versus preschool), it was difficult to determine whether the subtype of higher-order language deficits corresponded to the lexical-syntactic deficits or semantic-pragmatic deficits. Cluster 4 (average to above average phonology, average comprehension) did not meet criteria for a language disorder, but was conjectured to fit the semantic-pragmatic subtype, as these features were not directly assessed but were assumed to be present because of the ASD diagnosis. Therefore, there appears to be significant variability in language disability in ASD, which roughly maps onto established language disorder subtypes; and, regardless of the etiology of such deficits, a comorbid diagnosis would have clinical utility.

Conclusion

ASDs and language disabilities encompass a heterogeneous range of ability and disability. The relationship between the two disorders is complex: some individuals with SLI or ASD may belong in the same continuum of disability, whereas others may have etiologies that are distinct.

To further understand the relationship between the two disorders, more large-scale studies of families with a history of SLI or ASD need to be conducted. Furthermore, more longitudinal studies should be conducted to better understand the trajectory of language development in these disorders. However, regardless of etiology, it is important to carefully assess language functioning in individuals with ASD as well as social and adaptive functioning in individuals with language impairment, and to follow development across the lifespan, as there may be social and adaptive functioning deficits that are either not as apparent at younger ages develop later in life, or improve significantly with age. Furthermore, there needs to be careful assessment of individuals across several domains, including parent and teacher report as well as clinical observation, as diagnoses may differ if one puts undue emphasis on one type of measure. Finally, clinicians should be aware that there may be many people who do not neatly fit into the categories of "ASD" or "SLI," but who show features of either or both and which include 2q, 15q, and 16pneed intervention.

Treatment Implications

It is difficult to study the nature of the relationship between ASD and other disorders, as there are many subtypes of ASD with different etiologies as well as phenotypic presentations (with the further complication that the etiologies do not appear to map clearly onto phenotypic presentations). This is further complicated by the fact that there are many conditions that are frequently comorbid with ASD, as well as with each other, as discussed above. For example, it is not uncommon for symptoms of ID, ADHD, language impairment, and ASD to co-occur. Each person presents with his or her unique set of symptoms, skills, and learning abilities and disabilities. Strengths may include such skills as accumulation of facts, motor skills, or visual memory, and specific learning styles may include learning better in more structured settings, through significant repetition, or through visual inputs or the use of visual material to focus attention (Siegal 2010). There are also behaviors that seriously interfere with treatment, such as intense sensory interests, repetitive behaviors and preoccupations, which frequently prevent attending to other environmental stimuli, and other significant attention problems, as described above. Furthermore, although there is no widely accepted memory disorder diagnosis for children, children with ASD, more often than not, have learning and retention problems, sometimes obviously secondary to ID, and sometimes secondary to poor attention or comprehension during the learning period. These usually affect learning of material that is difficult for them to learn initially, such as language skills, but can also affect other types of learning, such as learning of facts that are within their language capability, or learning of math skills.

Given the tremendous variability in the presentation of ASD and the frequent presence of comorbid psychopathology, each child needs to be characterized in detail, considering the likelihood of impact from ID, attention and memory problems, language impairment and deficits in social cognition. The clinicians planning treatment should thoroughly assess each child for language level and profile, attention and memory function, visuospatial and motor functioning, social cognition and social skills, level of intellectual functioning, and presence of interfering preoccupations and repetitive behaviors. In addition, psychiatric/mood issues, such as poor sleep, anxiety, depression, and irritability, which are common in ASD, can very much impact availability for behavioral treatment, and may sometimes be successfully ameliorated with behavioral or medication approaches. Treatment for these problems do not address core autism deficits, may make behavioral and educational teaching of language and social skills more successful. Although there is treatment literature for each disorder (ASD, ID, ADHD, language disorders), which can be very usefully consulted, it is the specific symptoms, skills, deficits, and interfering behaviors that should dictate treatment. The response (or lack of response) to treatment should then guide whether to continue with or modify the treatment process.

Implications for Outcome

Treatment, and early commencement of treatment is important, as earlier age of diagnosis and treatment has been associated with better outcomes (reviewed by Helt et al. 2008). Studies also suggest that there are a higher-functioning subset of individuals who tend to improve over development and a lower-functioning group of individuals who continue to fall further behind their peers (Fein et al. 1999). Outcome studies also suggest that higher cognitive and language abilities in early childhood are associated with better outcomes (review by Helt et al. 2008). Other factors that may contribute to better outcomes include higher motor scores, better imitation skills, and a previous diagnosis of PDD-NOS (Helt et. al. 2008; Sutera et. al. 2007) as opposed to a diagnosis of autistic disorder. Comorbid conditions and subthreshold symptoms of conditions such as ID and language disorders contribute to making learning more impaired and reaching optimal outcomes more difficult. Furthermore, certain symptoms are more likely to be more resistant to remediation in individuals who improve to such an extent that they no longer meet criteria for ASD. These residual deficits include attention problems, anxiety, and subtle pragmatic language difficulties (Fein et al. 2005; Helt et al. 2008; Kelley et al. 2006; Sallows and Graupner 2005). These observations plus the literature reviewed above suggest that the interrelatedness of ASD, intellectual abilities, language functioning, and attention functioning is far from being completely understood, highly complex, and extremely important to unravel if the children are to reach the best possible outcomes. However, while research progresses, clinicians must assess each child with ASD in order to identify intellectual, attention, and language difficulties that may be remediable.

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4

Assessment of the Core Features of ASD

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Keywords
Assessment · Evaluation

History of ASD Assessment in Young Children

In his groundbreaking paper, "Autistic Disturbances of Affective Contact," psychiatrist Leo Kanner first described a group of children who shared a cluster of clinical symptoms characterized by impairment in social affect and skills coupled with resistance to change and unusual, stereotyped behaviors. He noted that the fundamental problem in these children was their "inability to relate themselves in the ordinary way to people and situations from the beginning of life" (Kanner 1943). Kanner borrowed the term "autistic" from Dr. Euguene Blueler who used the term to describe the withdrawal into one's self observed in individuals with schizophrenia. Despite the fact that Kanner specifically noted differences between the 11 children he studied and those with schizophrenia, many professionals in the early field of child psychiatry viewed these children as being severely mentally ill with early onset adult psychosis (Rutter and Schopler 1987). In the 1960s, the field of child psychiatry had yet to standardize diagnostic criteria for the "psychoses of infancy," which created contradiction and controversy in the assessment, diagnosis, and treatment of these disorders (Rutter 1967). It was not until the 1970s that "infantile autism" was identified as a distinct disorder apart from schizophrenia and soon thereafter earned its own set of diagnostic criteria, which was standardized in the DSM-III (APA 1980; Rutter and Schopler 1987; Volkmar and Klin 2005). DSM-III placed infantile autism in the new general category of Pervasive Developmental Disorders (PDD), which was indicative of a key reconceptualization of autism as a developmental, rather than a psychiatric, disorder (Volkmar and Klin 2005). Diagnostic criteria were broadened in the DSM-III-R (APA 1987) under the new term "Autistic Disorder" in recognition of children who developed the symptoms of "infantile autism" at later stages of development and who presented with varying levels of symptom severity (Volkmar and Klin 2005; Wing 2005). Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) was also added at this time to account for children with significant symptoms who did not meet full criteria for Autistic Disorder. However, the DSM-III-R criteria for Autistic Disorder proved to be too broad, which led to overdiagnosis of children with intellectual disability and

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underdiagnosis of higher functioning children with ASD (Volkmar and Klin 2005). The DSM-IV (APA 1994) refined and narrowed the diagnostic criteria for Autistic Disorder and added Asperger's Disorder to the category of Pervasive Developmental Disorders. As of this writing, the APA is considering another major revision in the forthcoming DSM-V which would subsume Autistic Disorder, Asperger's Disorder and PDD-NOS into one overarching category called ASD (Lord et al. 2011).

At the root of the controversies in ASD diagnostic criteria were fundamental differences in the conception and nature of autism among experts in the field. Some experts believed that Kanner's description of symptoms represented "true" autism, while others believed that Kanner's description was too narrow and did not account for the wide range of children with the disorder. Thus, early assessment instruments were not standardized and tended to emphasize some key deficits while ignoring others, depending on the theoretical orientation of the author (Parks 1988). As diagnostic criteria for ASD have been refined and altered over time, so too have assessment procedures and protocols.

Clinical Assessment of Autism Spectrum Disorders

Early screening Given the wide heterogeneity of features in children and the significant variance in presentation of the three core deficits currently implicated in ASD, making the diagnosis of ASD is particularly challenging. There is no one identifiable descriptor, genetic marker, or biological feature that can definitively indicate the presence of an ASD. However, with increasing awareness of ASD in the media and through the efforts of research and public agencies, a growing number of caregivers and providers are becoming more astute to the indicators of ASD.

Often the assessment process begins with parents raising concerns about their child's development. During regular office visits or well-child checks, parents may share their observations, videotapes, or written notes about red flags they have noticed regarding their child's development. For example, speech delay is a significant warning sign that is often readily detected by parents and often leads to a discussion of their concerns with their primary care physician (PCP). For other children, early social deficits such as being unresponsive to people, focusing intently on one object for long periods of time, or delayed or absent joint attention (JA) can be important signs. However, these cues are often more subtle and difficult to detect without formal screening and evaluation.

Given there is no specific biological or genetic marker for ASD, currently assessment must focus on the screening and evaluation of behavior (Filipek et al. 1999; Zwaigenbaum et al. 2009). Although there is room for ongoing improvement and expansion, screening and assessment efforts in young children are in high demand and are becoming more commonplace. Practice parameters for the detection and assessment of ASD have been published by many organizations such as the American Academy of Pediatrics (AAP; American Academy of Pediatrics Committee on Children with Disabilities 2006; Johnson, Myers, and American Academy of Pediatrics, Council on Children with Disabilities 2007), the American Academy of Neurology (Filipek et al. 2000b), the American Academy of Child and Adolescent Psychiatry (Volkmar et al. 1999), and a consensus panel with representation from various professional societies (Filipek et al. 1999). These parameters highlight two levels of the evaluation process: Level 1 which entails developmental surveillance and screening, and Level 2 which involves comprehensive multidisciplinary diagnostic assessments and evaluations by professionals who have significant experience with ASD.

Level 1 surveillance and screening According to the AAP (American Academy of Pediatrics Committee on Children with Disabilities 2006; Johnson and Blasco 1997; Johnson et al. 2007; American Academy of Pediatrics, Council on Children with Disabilities 2007) "surveillance" is the flexible and ongoing process of identifying children who could be at risk for developmental delays, while "screening" is the use of standardized tools at specific time points to verify risk and define it further. It is recommended that surveillance occur at every preventative visit during childhood and should involve attending to parent's concerns, gathering a developmental history, making observations of the child, identifying possible risk and protective factors, and keeping good records of this process and the findings. Screeners should be administered at any time point when concerns are raised through observations or during the surveillance process to identify potential developmental delays or deficits in communication, language, motor, social, and play skills. The AAP also recommends that screening with standardized assessment tools be used at specific time points (i.e., 9, 18, 24, 30 month visits) even if developmental concerns have not been raised.

PCPs often use screeners that assess for a wide variety of developmental concerns, medical issues, and childhood disorders, most of which involve parent report via paper and pencil questionnaires. The following is a brief summary of two of the traditional developmental screeners and a few of the standardized developmental screening instruments that are used in primary care practices. The Denver-II (DDST-II; Frankenburg et al. 1992) is a traditional tool for developmental screening for children from birth to 6 years of age. It obtains samples of receptive and expressive language, articulation, as well as fine motor, gross motor, adaptive, and personal-social skills. The Revised Denver Pre-Screening Developmental Questionnaire (R-DPDQ; Frankenburg 1986) was created to identify a subtest of children who need further screening from birth to age 6. Parents are asked to answer 10 to 15 items which cover a wide range of domains. According to Filipek et al. (1999), because the DDST-II and R-DPDQ lack sensitivity and specificity, better standardized measures must be used during Level 1 surveillance and screening to aid in the assessment of ASDs.

Examples of standardized parent report questionnaires with acceptable psychometric properties include: The Ages and Stages Questionnaire, Second Edition (ASQ; Bricker and Squires 1994, 1999; Squires et al. 1997); The BRIGANCE® Screens (Brigance 1986; Glascoe 1996) which assesses general knowledge, speech-language, fine and gross motor, graphomotor development, and reading and math; The Child Development Inventories (CDI; Ireton 1992; Ireton and Glascoe 1995) which screen for social, self-help, behavior, and health problems, as well as language motor, cognitive, and pre-academic skills; and The Parents' Evaluation of Developmental Status (PEDS, Glascoe 1998) which assesses parents' concerns about delays and disabilities (See Filipek et al. 1999 for a more detailed review).

It is important to note that many screeners used by pediatricians or primary care physicians at well-child checks may not always differentiate children with ASD from children with other developmental concerns (Filipek et al. 2000b; Johnson et al. 2007; American Academy of Pediatrics, Council on Children with Disabilities 2007), so it is important for physicians to administer follow-up screeners more specific to ASD if indicated as part of the Level 1 process. Some examples of autism-based screening tools include The Checklist for Autism in Toddlers (CHAT; Baron-Cohen et al. 1992), The Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al. 2001), and The Pervasive Developmental Disorders Screening Test-II Primary Care Screener (Siegel 2004). If scores are elevated on screeners and/or red flags are identified by observations or parent report, it is important that the PCP continue to Level 2 of the evaluation process and refer the child for a full multidisciplinary evaluation.

During surveillance and screening, another crucial component to the assessment process is providing parent education along the way (Johnson et al. 2007). By being knowledgeable about the characteristics and clinical symptoms of ASD, the evaluation process will likely run more smoothly and efficiently, as parents will have more information about what to expect from the process and be better able to articulate and describe their child's presentation and symptoms.

Level 2 comprehensive evaluation by multidisciplinary team Findings suggestive of ASD observed during Level 1 surveillance and screening warrant Level 2 multidisciplinary assessment.

Key disciplines that should be involved in the Level 2 evaluation process include clinical psychologists, school psychologists, social workers, speech and language pathologists, physical therapists, occupational therapists, audiologists, primary care physicians, neurologists, and developmental pediatricians. Within multidisciplinary teams it is important that one individual serves as the point person, which entails organizing the team of evaluators, communicating with the family and assessment providers to clarify and understand the referral questions, planning the components of the assessment, and relaying information to parents and treatment providers in the community who will carry out treatment recommendations (Ozonoff et al. 2005).

There is a strong professional consensus that interviewing parents about developmental milestones and detailed symptoms of ASD, as well as direct child observation, preferably with the assistance of standardized measures, are essential components of the evaluation process (Johnson et al. 2007; NIMH 2008; Ozonoff et al. 2005). The following is a brief overview of specific interview and behavioral observation components that should be included in a comprehensive evaluation.

A thorough intake should be conducted with the parents or primary caregivers of the child. An intake includes an in-depth interview about the child's prenatal, neonatal, and postnatal periods; developmental milestones reached and not reached; health and medical history; and behavioral and mental health histories. Critical aspects of history taking include gathering information about the child's communication, social, and behavioral development, as well as motor skills and adaptive functioning abilities. It is also imperative to listen to and review parent's current concerns, which may involve reviewing audio, visual, or written documentation. If available, review of past and current medical, psychiatric, assessment, treatment, and academic records will provide rich information from multiple perspectives and across various settings and contexts.

Physical examination by a PCP, pediatrician, or pediatric neurologist can provide observational information of the child and includes medical history taken from the child's caregivers. Additionally, physical examination may include searching for medical issues, co-morbid disorders, dysmorphic features, acquired brain injuries, and neurological abnormalities.

Developmental and psychometric evaluations are key factors in determining a child's overall level of functioning, cognitive abilities, adaptive skills, language skills, motor skills, and any potential behavioral or emotional concerns. Professionals with specific training in clinical assessments, psychometrics and test design, and test administration techniques should utilize standardized tools and assessments with acceptable psychometric properties to aid in the diagnostic process. These multidisciplinary assessments include observations, behavioral measures, and specific cognitive, academic, language, and motor skill assessments. Both strengths and weaknesses should be assessed. Whenever possible, interviews with and questionnaires from multiple sources such as teachers, providers, and family members should be obtained to provide a well-rounded picture of the child's behaviors, abilities, and functioning in a variety of contexts.

As previously stated, parents are a key component in the evaluation process. It is important to continue the assessment of the parent's knowledge of ASD, coping skills, and their available resources throughout the process and to make adjustments accordingly to ensure they and their children are being fully supported throughout the process. Further, the evaluation team should work closely with parents to provide them with regular updates with information about the assessment processes, review the assessment outcomes, discuss recommendations for intervention, and begin to provide education about intervention options.

In addition to the early screening and assessment of specific characteristics associated with ASD, it is also important to address factors outside of the three core domains of ASD to obtain a complete and holistic picture of the child. Information about the child's overall level of functioning in multiple areas such as language, cognitive, and adaptive abilities; age; environmental and family influences such as cultural factors and family mental health histories; and comorbid medical and mental health issues should be obtained and considered to address factors that might be contributing to the child's overall presentation, to identify strengths and weaknesses, and to assist with differential diagnoses. For example, many diagnoses should be considered in the evaluation process such as intellectual disability, borderline intellectual functioning, various developmental disorders including developmental language disorders (e.g., expressive language disorder), schizophrenia, selective mutism, and stereotypic movement disorder (APA 2000).

The multidisciplinary diagnostic evaluation entails assessment of a wide range of behaviors and domains of functioning in addition to the core domains of ASD. Many of the assessment tools used in a clinical evaluation focus on evaluation of the three core domains of impairment in ASD. There has been a significant amount of scientific work conducted in the exploration and development of appropriate and accurate evaluative measures related to the domains of impairment in ASD. In the next section we provide detailed descriptions of the core domains of impairment in ASD and the observational assessments, interview measures, questionnaires, and experimental procedures that have been developed to inform our characterization of ASD.

Assessment of the Three Core Domains of ASD

Social Domain

Definition At its core, ASD is a disorder of social interaction, marked by a lack of social initiation and reciprocity. This fact is reflected in DSM-IV-TR (APA 2000) criteria for Autistic Disorder and Asperger's Disorder, which require individuals to exhibit more behaviors indicative of impairment in social behavior than they are required to exhibit in the domains of communication and restrictive, repetitive behaviors. In order to assess young children who may be at risk for ASD, it is important to understand the unique social impairments that define it. DSM-IV-TR defines impairment in social interaction for Autistic Disorder and Asperger's Disorder as follows: (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 lack of showing, bringing or pointing out objects of interest); and (d) lack of social or emotional reciprocity. Diagnostic criteria for ASD were generated over time by research which indicated that children with ASD exhibit difficulties in specific social behaviors including eye gaze, social orienting, joint attention, face perception, imitation, empathy, and social reciprocity. These key social features will be explored in the following section.

Key features in the social domain One of the more striking features of many, though certainly not all, children with ASD is a lack of gaze or the tendency not to look directly into others' eyes. Orientation to others via eye contact is a critical biological trait that has evolved in humans as a regulator of myriad social encounters. Typically developing infants establish eye contact with their caregivers early and often; however, infants with ASD often fail to develop this skill (Carter et al. 2005). Furthermore, this failure to establish mutual gaze with caregivers appears specific to ASD and is not usually observed in children with other developmental delays including intellectual disability. It is important to note, however, that not all children with ASD display the same impairment in eye gaze. Some children with ASD express a clear preference not to make eye contact to the point that parents may have to hold their face to catch their eyes; other children with ASD may exhibit milder symptoms, such as brief eye contact or eye contact that is poorly modulated in social situations (Filipek et al. 1999).

Many children with ASD have impairments in social orienting skills. Social orienting may be defined as one's behavioral response to auditory or visual social stimuli, typically indicated by a head turn or eye gaze towards the stimulus.

Studies of social orienting focusing on visual and auditory preference in children with ASD have found that children with ASD, compared to matched controls, prefer nonsocial to social sounds (Dawson et al. 1998), prefer nonspeech sounds over speech sounds (Kuhl et al. 2005), prefer geometric patterns over social scenes with other children (Pierce et al. 2011), and show a lack of preference for point-light biological motion (e.g., a figure running) compared to random point-light motion (Klin et al. 2009). All of these studies indicate that children with ASD seem to possess a neurodevelopmental predisposition to attend to nonsocial stimuli over social stimuli.

Joint attention is another key social deficit in ASD and is defined as the sharing of an object or event with another person (Carter et al. 2005). Typically developing infants are able to follow a visual cue, such as pointing or a shift in gaze, between 6 and 18 months of age (Mundy and Burnette 2005). However, children with ASD exhibit marked impairment in joint attention as evidenced by a lack of response to shifts in gaze, pointing, or other nonverbal gestures, as well as a lack of initiation of joint attention with others. Thus, joint attention embodies two complementary concepts: the *response to joint attention* (RJA) and the *initiation of joint attention* (IJA). Most typically developing children will follow a caregiver's point to something of interest in the distance (RJA) or they might try to point out something themselves in order to share their interest with another person (IJA). Joint attention skills form a basis of social sharing and engagement with others and they are significantly impaired in children with ASD. While some children with ASD may point at an object of interest in the distance, they usually do not coordinate their gaze back to another person to share the experience with them. Also, children with ASD may point or gesture at something, but typically this gesture is not well coordinated with eye contact and serves to satisfy a need rather than to initiate a social encounter with another person (Baron-Cohen 1989; Carter et al. 2005).

Many children with ASD also exhibit impairments in imitation. Imitation is the vehicle through which children develop simple to highly complex skills, ranging from social smiling to language acquisition. Typically developing children may be observed mimicking their caregivers' facial expressions as infants and, later, their nonverbal gestures, such as waving, pointing, and blowing kisses. As they get older, these children learn to play simple games like peek-a-boo and begin to imitate the actions of their caregivers. Many studies have shown that children with ASD tend to have difficulty imitating simple actions involving objects, body movements, and facial expressions and that these deficits are associated with impaired social development (Rogers et al. 2005).

Another core feature of many children with ASD is "aloofness" and lack of understanding of and empathy towards others. This lack of empathy manifests itself in atypical behaviors. For example, a child with ASD may run over another child, as if the child were an object, to get to a slide on a playground. Similarly, this child may not respond or offer comfort when another child is hurt or may laugh at socially inappropriate times. One theory that seeks to explain this social impairment in autism is "theory of mind," proposed in 1995 by Simon Baron-Cohen. Dr. Cohen hypothesized that the inability to infer others' mental states (e.g., intentions) and to attribute mental states to self and others was a core feature of autism. He later expanded his theory of mind to include deficits in empathizing, noting that if one is unable to infer others' mental states, then one is also unable to have an affective response (e.g., a facial expression) that is appropriate to others' mental states (Baron-Cohen et al. 2005).

ASD is perhaps best understood as a disorder of social reciprocity. Reciprocity is defined simply as "mutual exchange" and is a cornerstone of our growth and survival as a species. Human lives are interconnected, and we have developed highly specialized social skills to navigate the many complicated exchanges we experience with others on a daily basis. Reciprocity is the act of giving and taking in partnership with others and to each other's mutual benefit. Typically developing children learn about giving and taking in the earliest stages of life. Parents show and share

Table 4.1 Behaviors warranting further assessment

Behaviors between birth and 1 year of age	Behaviors from 1 to 3 years of age
Limited ability to anticipate being picked up	Abnormal eye contact
Low frequency of looking at people	Limited range of facial expressions
Little interest in interactive games	Limited social referencing
Little affection towards familiar people	Limited sharing of affect/enjoyment
Content to be alone	Limited interest in other children
	Little interest in interactive games
	Limited social smile
	Limited functional play; no pretend play
	Low frequency of looking at people
	Limited motor imitation

objects with their children early on to their delight and wonder. Children soon learn that when they show and share objects to their parents, they are rewarded with smiles, giggles, and affection. Some children with ASD do not learn to show or share with others or do so inconsistently or on a limited basis. Similarly, many children with ASD have difficulty engaging in social games that require imitation, such as peek-a-boo or the tickle game, and, if they do participate, do so in a non-reciprocal way (e.g., by being tickled only and not tickling back). As children mature, the social landscape becomes even more complex and children who do not learn the skills of social reciprocity have great difficulty developing friendships with their peers. Several studies of young children with ASD indicate that they initiate social interaction with peers less frequently than other children and are less responsive to others' initiations (Travis and Sigman 1998).

Many studies have illustrated that children with ASD have significant deficits in face perception. Schultz (2005) identifies two types of face perception in ASD research: (1) Recognition of a person's identity via the structure of the face and (2) Recognition of the internal affective state (emotion) of another person via changes in facial expression. These skill deficits may have obvious negative repercussions in social development as perception of faces is a springboard for social initiation, friendship, and a foundation for empathy (Dawson et al. 2005).

Assessment of the social domain While impairment in social functioning is universal for children on the autism spectrum, symptom presentation will vary depending on the developmental stage and cognitive ability of the child. Clinicians who assess social functioning in young children at risk or suspected of having ASD must possess knowledge of typical child development in order to ascertain whether key social milestones are being met. Chawarska and Volkmar (2005) summarized the following behaviors in early social development that distinguish children with ASD from typically developing and developmentally delayed peers. Table 4.1 highlights behaviors indicating further assessment is warranted.

Many instruments are now available for the assessment of ASD in young children and will be highlighted in the instruments listed below.

Observational methods One of the most commonly used observational measures in the assessment and diagnosis of ASD is the Autism Diagnostic Observation Schedule (ADOS; Lord et al. 1999). The ADOS is a semi-structured standardized assessment instrument that creates many opportunities for an examiner to observe any social difficulties through the use of play and activities designed to foster social communication with a child such as blowing bubbles, looking at pictures, and reading stories. The ADOS comprises four different modules, which have been carefully designed to match the language ability and developmental level of the child, ranging from preverbal/single words to fluent speech. A toddler version of the ADOS (ADOS-T; Luyster et al. 2009) has been developed to ascertain deficits in children under 24 months.

All versions of the ADOS can be administered in 30–45 min. For younger, more cognitively and verbally impaired children, key social behaviors assessed include showing, pointing, coordination of gaze, frequency of vocalizations directed to others, and joint attention. For older children with fewer to no verbal or cognitive limitations, key social behaviors assessed include insight into the nature of interpersonal relationships, the amount of reciprocal social communication, and quality of social response. All individuals, no matter their age, verbal, or developmental level are also assessed in the following social skill areas: unusual eye contact, facial expressions directed to others, gestures, shared enjoyment in interaction, quality of social overtures, and overall quality of rapport.

The Childhood Autism Rating Scale, Second Edition (CARS2; Schopler et al. 1988; Schopler et al. 2010) is an observational rating scale that is used to assess behaviors associated with ASD in children 2 years and older. The CARS2 consists of 15 items on which the child is rated by a trained clinician using a 4-point scale based on their interactions with and observations of the child. The ratings take into consideration the frequency, intensity, peculiarity, and duration of the behavior. There are three forms included in the CARS2: the Standard Version Rating Booklet (CARS2-ST) appropriate for children under 6 years of age, the High-Functioning Version Rating Booklet (CARS2-HF) appropriate for children over 6 years of age, and the Questionnaire for Parents or Caregivers (CARS2-QPC) which aids in scoring both the ST and HF versions. Specific social skills assessed using the CARS2 include interpersonal relationships, emotional responses, and imitation.

The Early Social Communication Scales (ESCS; Mundy et al. 2003) is an observational measure designed to assess nonverbal social-communication skills. The three main behaviors of interest are joint attention behaviors (i.e., does the child use nonverbal behaviors to share their experiences pertaining to objects and events), behavioral requests (i.e., does the child use nonverbal behaviors to request help during events or to obtain objects), and social interaction behaviors (e.g., does the child engage in turn-taking interactions with others). The assessment also differentiates whether the behaviors are child-initiated versus responses to the examiner's bids.

The Communication and Symbolic Behavior Scales Developmental Profile (CSBS DP; Wetherby and Prizant 2002) is a screening tool administered by a trained professional that utilizes direct observation to assess social communication skills in young children. The social domain is divided into three major sections that assess specific behaviors: (1) emotion and eye gaze (gaze shifts, shared positive affect, gaze/point following), (2) communication (rate of communicating, behavior regulation, social interaction, and joint attention), and (3) gestures (conventional gestures, distal gestures).

Other standardized, normed assessments of related social abilities include measurements of face recognition (NEPSY-II, Korkman et al. 2007) and face memory (Children's Memory Scales: Face Memory Subscales; Cohen 1997).

Interview formats The Autism Diagnostic Interview-Revised (ADI-R; Lord et al. 1994) is an extended parent interview used in the assessment of ASD that typically takes 1.5 to 2.5 h to administer by a trained professional. The ADI-R consists of 93 items, 17 of which are grouped into the "social development and play" category. Specific items from this category are then chosen for the ADI-R diagnostic algorithm, which mirrors DSM-IV-TR criteria in the social domain for Autistic Disorder and Asperger's Disorder. Thus, DSM-IV-TR criterion (a) "marked impairment in the use of multiple nonverbal behaviors" is assessed by questions probing for a child's use of direct gaze, social smiling, and range of facial expression; criterion (b) "failure to develop peer relations" is assessed by questions which ask about the child's interest in and response to other children, group play with peers, and friendships; criterion (c) "lack of spontaneous seeking to share enjoyment" is assessed by questions which probe whether a child is actively showing things of interest, offering to share things with others, or seeking to share his/her own enjoyment with others; criterion (d) "lack of social emotional reciprocity" is assessed by questions which probe for quality of social overtures, inappropriate facial expressions (i.e., those that are incongruent to the situation and indicate a lack of understanding of others' affective states), appropriateness of social response, and the act of offering comfort when others when are hurt or ill.

The Vineland Adaptive Behavior Scales, Second Edition (VABS-II; Sparrow et al. 2005) is a 30–45 min parent interview that assesses a child's adaptive functioning in the domains of communication, daily living skills, socialization, motor skills, and maladaptive behaviors. The VABS-II is used frequently with children suspected of ASD, intellectual disability, and developmental delay. Within the socialization domain, children are assessed in the areas of interpersonal relationships, play and leisure time, and coping skills.

Questionnaires Questionnaires that assess social functioning can be very useful in assessing the social domain. The Social Communication Questionnaire (SCQ; Berument et al. 1999; Rutter et al. 2003a) is a 40-item "yes/no" questionnaire that can be completed by a parent or caregiver in about 10 min. The questions directly mirror those of the ADI-R and provide evidence of social deficits as well as challenges in communication and behavior. The SCQ has both *Lifetime* and *Current* forms which can be used to focus on a child's developmental history or present functioning, respectively, in the three core domains of impairment in ASD.

The Social Responsiveness Scale (SRS; Constantino 2002) is a 65-item scale that assesses the severity of symptoms associated with ASD, has both parent and teacher report forms, and can be completed in about 15 min. Behaviors are divided into the following five subscales: receptive, cognitive, expressive, and motivational aspects of social behavior, as well as autistic preoccupations. Besides subscale scores, the SRS generates a total score indicative of overall social impairment.

The PDD Behavior Inventory (PDDBI; Cohen et al. 2003) is a parent/teacher rating scale that was designed to aid professionals in evaluating the treatment progress of children with ASD and related disorders. The PDDBI comes in a standard form (124 items; 20–30 min) and extended form (180–188 items; 30–45 min), depending on the needs of the assessor. The standard form focuses on behaviors specific to ASD in the three core domains and the extended form includes behaviors that are not solely related to ASD, such as aggression and specific fears. Key social skills assessed include social pragmatics and social approach.

The Infant/Toddler Social Emotional Assessment (ITSEA; Carter and Briggs-Gowan 2000) is a 166-item parent/caregiver scale used to assess developmental strengths and weaknesses in young children. It may be completed by a parent/caregiver or administered as a structured interview. The ITSEA comprises four broad domains: externalizing, internalizing, dysregulation, and competence. The competence domain includes the social skills of compliance, attention, imitation/play, mastery motivation, empathy, and prosocial peer relations. Elevated scores in any subdomain are classified as "Of Concern" and may indicate the need for early intervention services.

The Social Skills Improvement System Rating Scales (SSIS; Gresham and Elliott 2008) measures social skills, problem behaviors, and academic competence in children ages 3–18. It may be completed by a parent, caregiver, or by the student. The social skills of communication, cooperation, assertion, responsibility, empathy, engagement, and self-control are assessed. An "Autism Spectrum" subscale was added to the newest published version.

Experimental approaches A wide variety of experimental measures have been employed to quantify the social functioning of children in ASD. A description of all the behavioral, psychophysiological, and imaging paradigms used to characterize the social challenges noted in ASD is beyond the scope of this chapter, but a few experimental measures will be briefly described to provide the reader with some insight into the tools available to scientists.

Atypical eye gaze is one of the primary features noted in ASD. Eye-tracking technology has elucidated significant differences between the use of gaze in children with ASD and matched controls. Many studies indicate that while typically developing children focus on the eyes of others, children with ASD tend to focus instead on the mouth, body, or even objects (Klin et al. 2002). Findings using this technological approach have indicated the utility of eye-tracking paradigms to assess social impairments in ASD and suggest that a toddler's failure to orient to a caregiver's gaze is an early disruptor of socialization and language acquisition (Jones et al. 2008).

As described above, children with ASD show reduced attention to information in the social world. Dawson et al. (1998) illustrated this key deficit in a novel experiment in which children with autism were compared to children with Down syndrome and typical development in their ability to orient towards auditory social stimuli and nonsocial stimuli. Results indicated that children with autism were significantly more impaired than the other children in responding to both types of stimuli, and their lack of response to social stimuli was even more pronounced. In this social orienting assessment a child sits across from an experimenter and is presented with auditory stimuli. From four locations around the room, a second experimenter delivers social (e.g., calling child's name, clapping hands) and nonsocial (e.g., car horn honking, kitchen timer) sounds. Each sound is presented for approximately 6 s, at the same decibel level, and once in the child's left and right visual field and once 30 degrees behind the child to the left or right. The number of times the child orients to the sound is summed.

Since DeMeyer and colleagues' first report of imitation deficits in ASD (DeMeyer et al. 1972), a number of experimental tools have been developed to assess imitation abilities in young children with ASD (Smith et al. 2006). Of the experimental measures, the Motor Imitation Scale (MIS; Stone et al. 1997), a 16-item scale based on Piaget's developmental sequence, shows good psychometric properties. Several studies with ASD have also utilized the gestural imitation battery from Uzgiris and Hunt's sensorimotor scales (Uzgiris and Hunt 1975).

The assessment of empathy has been assessed experimentally using the response to distress task (Sigman et al. 1992). In this paradigm, while seated across from a child, the experimenter pretends to bang a finger with a toy hammer and then proceeds to cry for a short period of time. The amount of time the child spends attending to the crying experimenter is tallied offline by coders blind to child group status. Children with ASD have been found to attend less to crying experimenters than their typically developing peers (Sigman et al. 1992).

The use of facial expressions in ASD has been assessed with the Maximally Discriminative Facial Movement Coding System (MAX; Izard 1979). Results from the use of this assessment instrument indicated children with ASD were more neutral in their facial expressions and displayed more ambiguous expressions than comparison children (Yirmiya et al. 1989).

Several experimental measures have been developed to assess "theory of mind" abilities in young children with ASD. In the *Sally and Anne task* (Baron-Cohen 1985) the child observes a model put an object in one location and then watches the object be moved by another without the model being aware of the move. The child must then identify where the model would look for the object. The *Smarties task* (Perner et al. 1989) calls one's own experience into the scenario. A child is shown a Smarties box that contains another object and then asked what others would think would be in the box. The *Charlie Test* (Baron-Cohen et al. 1995) utilizes a nonverbal approach in which a child looks at a picture of Charlie looking at one of four tasty treats. The child must infer from Charlie's gaze which sweet Charlie likes the most. Children with ASD show impairments in these three theory of mind tasks.

Face processing impairments have been described using electrophysiological paradigms. Electrophysiological studies require only passive viewing, rendering language and behavioral responses unnecessary, and making these paradigms appropriate for young children of all functioning levels. The presentation of faces elicits a well-described pattern of activation in the brain,

Table 4.2 Red flags in the communication domain

Red flags
No babbling, pointing, or other gesture by 12 months
No single words by 16 months
No two-word spontaneous (non-echolalic) phrases by 24 months
Loss of language or social skills at any age

or event related potential (ERP). The latency and amplitude of select ERP components, such as the face specific, negative going wave that is observed approximately 170 ms after viewing a face can then be analyzed as a measure of face processing brain activation. Findings from studies employing these paradigms indicate individuals with ASD show atypical activation to neutral and fearful faces (Dawson et al. 2004; Webb et al. 2006) and upright and inverted faces (McPartland et al. 2004).

There are many options available for clinicians and scientists to utilize in the assessment of social abilities in young children with ASD. These measures range from standardized questionnaires with good psychometric properties to experimental, psychophysiological paradigms conducted with small samples and limited control groups. Given the heterogeneity in presentation of children with ASD, broad-based measures as well as assessments focused on specific aspects of social cognition are all needed to contribute to the understanding of the social deficits in ASD.

Communication Domain

Definition A second core domain of ASD is communication. Communication is a broad term that refers to the giving and receiving of information through spoken language and sounds, written language, gestures, sign language, and body language (Paul and Wilson 2009). It is important to consider the different components of communication as the evaluation of communication, language, and speech overlap and can involve their own processes and assessment measures.

Impairment in communication can range from total lack of language, or an absence of an apparent desire to communicate, to excessive or formal speech with poor reciprocal conversation abilities. The DSM-IV-TR (APA 2000) diagnostic criteria for the communication impairment component of Autistic Disorder requires at least one 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; and (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

Key features in the communication domain The communication domain encompasses a large variety of speech, language, communication, and play-related deficits. Speech delays or language deficits, particularly difficulties with expressive language, are the most common concerns shared by parents about children between age 1 and 5 years (Filipek et al. 1999). Other common communication concerns that parents report include: difficulties with sharing needs, not pointing or using other common gestures such as waving, and regression in the use of words (Filipek et al. 1999). Early communication deficits also include accompanying behaviors or difficulties with pragmatics such as lack of appropriate gaze integrated with communication, lack of reciprocal (alternating to-and-fro pattern) vocalizations between child and caregiver, lack of or decreased use of gestures to communicate wants and needs, and delayed babbling after 9 months of age (Johnson et al. 2007). Table 4.2 lists several communication-based red flags that warrant immediate evaluation for possible ASD as identified by the American Academy of Neurology and Child Neurology Society (Filipek et al. 2000b).

In addition to the early signs of communication deficits, there are several other communication, language, or speech difficulties observed in ASD.

For example, some children use spoken language, but demonstrate atypical use of language, such as employing more formal or articulated speech, echolalia (immediate or delayed repetition of others' speech), or atypical tonal or rhythm qualities. Some children also have difficulties with using correct pronouns or may use neologisms (a made up word) or literal idiosyncratic phrases. Children who have adequate speech may show communication deficits through impairment in initiating or sustaining conversations with others or staying on topic of mutual interest (Filipek et al. 1999; Johnson et al. 2007).

Regression of language, speech, or communication is another significant indicator of ASD. It is estimated that 25 to 30% of children with ASD have exhibited language for some period of time but then stop, typically between 15 and 24 months of age (Tuchma and Rapin 1997; Turner et al. 2006). Regression can be sudden or gradual and can be accompanied by other losses such adaptive functioning abilities, loss of communicative gestures (e.g., pointing), or loss of social skills such as eye contact (Rogers 2004).

Play skills are also captured under the communication domain of ASD. Some children with ASD may play with toys, miniature objects, or dolls in a repetitive and mechanical way and demonstrate less flexible use or representation of objects. Other children may use toys or objects appropriately in a functional manner, but struggle with engaging in creative and imaginative play such as having dolls or action figures interact as agents or pretending that a block is a cup. Very verbal children may create fantasy worlds where certain topics become the center of their play and they struggle to play anything else (Filipek et al. 1999).

To capture the wide variety of possible communication deficits in ASD, multiple assessment procedures including observations, parent report, questionnaires, standardized language assessments, and experimental methods can be utilized. The following is a brief summary of assessment tools that are available to evaluate a child's overall communication abilities, specific communication and language-related strengths and weaknesses, and possible red flags and indicators of ASD.

Assessment of the communication domain As stressed previously, the evaluation of communication skills and deficits should ideally include a comprehensive, multidisciplinary assessment that involves behavioral observations, parent report and interview, questionnaires completed by individuals familiar with the child, and standardized instruments to assess abilities. Additionally, if there are red flags within the domain of communication, it is especially important for the child to be evaluated by a speech and language therapist or pathologist and to undergo an audiological evaluation if indicated, as these professions are highly specialized in the assessment of hearing, communication, language, and speech. Next is a review of possible tools that can be used for the assessment of the communication domain of ASDs.

Observational methods Structured behavioral observations and standardized measures of behavior provide specific opportunities for children to demonstrate their communication, speech, language, sign and gesture abilities. More specifically, observations allow clinicians to look for the presence or absence of a variety of communication skills by creating opportunities for conversation, social interaction, play or other scenarios (in clinical or laboratory settings) where communication of some sort would typically be present. There are very few standardized observational measures designed specifically for the assessment of the communication domain of ASD. Below is summary of the most well-known measures to date.

As described above in the social domain, the ADOS examines components of communication in addition to the social and behavioral domains. Language and communication use, speech, pragmatics, and play are all coded after careful administration of the instrument. First, the ADOS provides opportunity to assess a child's overall level of language (i.e., does he/she use mostly single words, no words, two-three word phrases, or phrase speech), the amount of verbal social overtures and verbal maintenance of the examiner's attention, and whether echolalia is present (the immediate or delayed repetition of the last statement or series of statements heard). Conversation ability is also assessed by focusing on whether the child verbally shares information, asks questions, engages in social chat, and how well he/she is able to build and carry on to-and-fro conversations. Second, the ADOS allows the examiner to listen to aspects of speech patterns and abnormalities that are associated with ASD such as flat or exaggerated intonation, little variation in tone or pitch, unusual volume, or a slow or quick rate of speech. Additionally, the examiner evaluates the presence of highly repetitive utterances with consistent intonation patterns (stereotyped or idiosyncratic use of words). Third, the ADOS assesses for pragmatic aspects of communication. The use of gestures such as pointing, as well as descriptive (holding arms out to indicate size), conventional (clapping for "well done"), instrumental, or informational gestures (shrugging, head nodding, or head shaking) are observed. Fourth, functional and imaginative/creative play are also assessed through observations and interactions during the ADOS. The examiner looks for whether the child spontaneously plays with a variety of toys, how the child plays with the toys (i.e., uses the toys in a cause-and-effect or functional manner, imitates use of toys, or uses figures as agents of action), and how flexible and creative is the use of toys. Overall, the ADOS is considered to be a "gold standard" for the observational and interactive assessment of ASD and provides an opportunity to obtain a snapshot of a child's overall communication skills.

As described above, The Childhood Autism Rating Scale, Second Edition (CARS2) provides observational information regarding ASD. In regard to the communication domain the CARS2 provides a measure of both verbal and nonverbal communication skills including functional speech, echolalia, pronoun reversal, peculiar words or jargon, and gestures such as pointing. Similarly, as described above, The Early Social Communication Scales (ESCS) is a structured observation-based measure designed to assess nonverbal social communication skills in young children while The Communication and Symbolic Behavior Scales (CSBS) uses direct observation and parent interview to assess for communication impairments and delays in addition to examining social communication skills. The CSBS has 18 subscales that measure various aspects of communication including communicative functions, use of gestures and vocals, gaze shifts, affect, and reciprocity, as well as four scales that measure symbolic development such as constructive and symbolic play. The Developmental Play Assessment Instrument (Lifter 2000) taps into the play skills component of the communication domain of ASD by investigating a child's level of pretend play and the frequency of a variety of play activities. The Play Assessment Scale (Fewell 1986) is a play-based measure that can be administered by a teacher, parent, researcher or another adult familiar with the child and the measure. It consists of two conditions: one involves examining the child's spontaneous play with one set of toys, while the other entails eliciting "a higher level" of play behavior in response to verbal prompts (e.g., will the child offer a fork in response to an "I'm hungry" prompt).

There are also several standardized assessment options that offer direct assessment of communication and language and can provide valuable information about a child's current abilities and weaknesses. These measures are typically administered in a clinical or research setting and are administered by trained psychologists, school psychologists, or speech and language professionals. The following is a brief summary of a small selection of the many communication and language assessment measures that are commonly used in the assessment of communicative abilities in ASD. The Comprehensive Assessment of Spoken Language (CASL; Carrow-Woolfolk 1999) is an oral assessment of language for ages 3 to 21 that measures lexical/semantic language, syntax, supralingustic abilities, and pragmatics. The Clinical Evaluation of Language Fundamentals—Preschool, 2nd Edition (CELF-P2; Semel et al. 2003) and The Preschool Language Scales, 5th Edition (PLS-5; Zimmerman et al. 2011) also assess a broad range of language skills for preschool children. The Peabody Picture Vocabulary Test—Fourth Edition (PPVT-4; Dunn and Dunn 1997) assesses receptive language skills through the use of a variety of pictures while its co-normed companion, The Expressive Vocabulary Test, Second Edition (EVT-2; Williams 2007) tests expressive vocabulary and word retrieval. The Test of Early Language Development—Primary: Third Edition (Newcomer and Hammill 1997) also measures receptive and expressive language and yields an overall spoken language score.

Interview format Parents are often the first to identify problems with speech or language and parents are the best resource for information about their child's language milestones, current abilities, any language loss, as well as social communication and pragmatic skills. The ADI-R, described above in social assessments, dedicates 21 items to investigating language and communication skills and deficits. Clinicians using the ADI-R assess a child's overall level of language by asking questions about the child's comprehension of spoken and overall language ability. Items on the ADI-R address the presence of abnormal language such as stereotyped and repetitive patterns of verbal and nonverbal language (e.g., neologisms, idiosyncratic language, verbal rituals). The ADI-R interviewer also asks parents to describe their child's speech and various deficits that could be present (e.g., articulation/pronunciation difficulties, intonation/rate/tone volume of speech, pronominal reversal). Social aspects of communication such as the frequency and quality of social chat, reciprocal conversation, and inappropriate statements are investigated. Clinicians using the ADI-R also gather information about nonverbal aspects of communication. For example, parents are asked whether their child uses another's body to communicate (e.g., using another person's hand to perform some sort of task like opening a door). The frequency and quality of gestures such as pointing to express interests, nodding and head shaking, and conventional and instrumental gestures (e.g., blowing a kiss, clapping, finger to lips) are also discussed.

As described above, The Vineland Adaptive Behavior Scales, Second Edition (VABS) is a parent interview that provides information about a child's adaptive skills. Within the communication domain, the VABS assesses expressive, receptive, and written language abilities.

Questionnaires There are a number of questionnaires that address various aspects of the communication and language impairments associated with ASD (along with the other two domains) including the following: The Social Communication Questionnaire (SCQ), The Social Responsiveness Scale (SRS), The PDD Behavior Inventory (PDD-BI), The Children's Communication Checklist—2nd Edition (CCC-2; Bishop 2006), and The Gilliam Autism Rating Scale (Gilliam 1995). The communication component of these questionnaires inquire about a child's skills or deficits in the areas of quantity and quality of language and gestures, give-and-take conversations, the ability to keep up with the flow of conversations, communication of feelings, being able to answer questions, and tone of voice. Additionally, The MacArthur-Bates Communicative Development Inventories—3rd Edition (MCDI; Fenson et al. 2007) is a communication-specific questionnaire that assesses emerging language skills by asking parents about what spoken words and sentences, as well as gestures, their child uses.

Experimental approaches The examination of the language and communication deficits observed in ASD has largely utilized the variety of standardized questionnaires, observations, and interviews available. However, many experimental measures assessing language and communication in ASD have been reported in the literature. While a review of all the experimental measures is beyond the scope of this chapter, we will highlight some of the experimental measures that have been described in the literature.

At the behavioral level, pragmatic language use has been assessed using the pragmatic rating scale (Landa et al. 1992) which provides a coding system for rating a variety of behaviors based on communicative interactions. Although originally developed for use with family members of individuals with ASD, the instrument has highlighted the impairments in reciprocity and intonation in adolescent children with ASD (Paul et al. 2009). The coding of contingent utterances based on recorded samples of spontaneous speech has also been utilized to assess pragmatics (Tager-Flusberg and Anderson 1991). The Profiling Elements of Prosodic Systems in Children (PEPS-C) task has been utilized to assess prosody in autism (Peppe et al. 2007). The task assesses prosodic skills at the basic level of auditory discrimination and production of prosodic change, and at the level of using prosody to communicate through the child's responses to questions pertaining to visual and auditory stimuli.

Electrophysiological and imaging paradigms have also been developed to assess aspects of communication in ASD. Examination of Mismatch Negativity (MMN), an event related potential component that responds to an odd stimulus among a sequence of similar stimuli, has been used to assess phonological processing abilities. With this approach, children with ASD have failed to show the expected MMN response to changes in syllables suggestive of phonological processing deficits (Kuhl et al. 2005). In an examination of word boundary identification, high functioning boys with ASD and controls listened to two artificial languages which contained either statistical cues or statistical and prosodic cues to indicate word boundaries. The boys with autism did not show the expected reduction in fronto-temporal-parietal circuit activation with the increase in word boundary cues nor did they show the learning related neural activation increases to the languages over time (Scott-Van Zeeland et al. 2010). The wide range of experimental assessments utilized in studies of language in ASD mirrors the breadth of experimental tools available for assessment of the social and behavioral domains. However, relative to these two domains, there have been fewer standardized assessment instruments developed to assess the behavioral domain in young children with ASD.

Repetitive and Restrictive Interests and Behaviors Domain

Definition The third core domain of ASD concerns restrictive interests and repetitive or stereotypic behaviors. Repetitive and restrictive interests and behaviors encompass qualitative deficits in a variety of behaviors such as repetitive or stereotyped movements, inflexible routines, intense interests, or preoccupation with parts of objects. The DSM-IV-R (APA 2000) diagnostic criteria for the restricted, repetitive, and stereotyped behaviors, interests, and activities component of Autistic Disorder requires at least one of the following: (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in its intensity or 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.

Key features in the restricted/repetitive interests and behavior domain Restrictive and repetitive behaviors (RRBs) in ASD can range from extreme and obvious to subtle and infrequent. Although many children with ASD can appear physically normal, many exhibit odd repetitive movements that distinguish them from other children (NIMH 2008). One common restrictive and repetitive behavior (RRB) in ASD is an encompassing preoccupation with a stereotypic or restricted pattern of interest that is abnormal in its intensity or focus. Restrictive interests involve topics, items, or hobbies that a child might be particularly enamored with or have intense interest in learning about such as mechanical (e.g., fixing tires or vacuum cleaners) or cognitive themes (e.g., train schedules, dinosaurs, video games). Some children may ask the same question repeatedly or share information about their interests regardless of the interests of or responses given by others.

Preoccupations with parts of objects and sensory interests also fall under this domain. Examples include chewing on chords or strings, lining up toys in a particular way or pattern, spinning wheels on toys, or watching ceiling fans spin around and around. Some children may collect things or objects for no particular purpose. Others may engage in repetitive actions such as opening or closing doors or turning light switches on and off. Repetitive touching, sniffing, or mouthing of objects may also occur.

Another component of the RRB category is inflexible adherence to certain nonfunctional routines or rituals. Inflexibility and rigidity may include adhering to certain routines in home and school environments. Many children are preoccupied with sameness and keeping their everyday routine consistent with little change. Some children engage in mealtime, dressing, or bedtime rituals that are abnormal in their intensity. Significant resistance to change is also common for some children with ASD. Tantrums or refusals to do an activity are not uncommon reactions to transitions or changes in routines.

Stereotyped and repetitive motor mannerisms or whole complex body movements are also seen in some, but not all children with ASD (Filipek et al. 1999). Odd repetitive motions otherwise known as stereotypies may include arm flapping, hand clapping, or finger flicking. Some children may spin in circles, rock back and forth, run aimlessly, or walk on their toes.

Additionally, research has been devoted to investigating the function of RRBs, which suggests RRBs may have a variety of purposes including sensory stimulation, perceptual reinforcement, situation avoidance, and attention seeking (Kennedy et al. 2000; Lovaas et al. 1987).

Assessment of repetitive and restrictive interests and behaviors Although the assessment of the social and communication domains of ASD is challenging, the assessment of repetitive and restrictive behaviors can be more complicated for a number of reasons. First, repetitive and restricted behaviors are often common in a variety of disorders other than ASD, including, obsessive compulsive disorder, Tourette's syndrome, and various mood and anxiety disorders (Bodfish et al. 2000; Cuccaro et al. 2003; Lewis and Bodfish 1998; Mahone et al. 2004). Although RRBs are common in many disorders, research suggests RRBs may occur more frequently and may be more severe in some individuals with ASD (Bodfish et al. 2000; Carcani-Rathwell et al. 2006; Osterling et al. 2002). Although many studies indicate in general, social and communication impairments are more common than RRBs in very young children with ASD, there is emerging evidence that some RRBs are evident in children as young as age 2 (Richler et al. 2007). For example, Lord et al. (2006) revealed that RRB domain scores at age 2 were predictive of ASD at age 9. In a sample of 2-year-olds, Richler et al. (2007) found children with ASD had higher rates of repetitive sensory motor (RSM) behaviors (approximately three) than children with developmental delays and typically developing children (about one or less). These researchers proposed having one RSM behavior may not be indicative of ASD, but having several or severe RSM might be suggestive of ASD. Additional studies are needed to identify and evaluate RRBs in young children. Second, RRBs may not always occur every day or be observable in short clinical or research sessions. Third, RRBs are varied, on a continuum from mild to severe, and may not manifest in the same way for each child, making RRBs particularly difficult to assess. Additionally, RRBs are often not stable over time and may change in type or frequency (Militerni et al. 2002). Therefore, if possible, it is imperative that a variety of assessments are utilized, that observations are made in multiple contexts, and that information is obtained from many sources. The following is a summary of observation-based, interview, questionnaire, and experimental measures used for the assessment of RRBs associated with ASD.

Observation The ADOS allows for the observation of RRBs during the variety of structured and play-based activities. Possible RRBs that can be evaluated if they occur include repetitive hand, finger, and other complex mannerisms; self-injurious behavior; repetitive interests and stereotyped behaviors, and unusual sensory interests in play materials or persons. However, it is important to note there are no specific "presses" (created opportunities) specifically for repetitive or restricted behaviors, thus they cannot be reliably assessed (Ozonoff et al. 2005). Subsequently, additional observations and reports from multiple sources may be needed in order to confirm or rule out the possibility of these behaviors. Repetitive and restricted behaviors may be observed through informal behavioral observations throughout the evaluation process and should be noted.

The Repetitive and Restricted Behaviour Scale (RBS; Bodfish et al. 1999) and The Repetitive and Restricted Behaviour Scale-Revised (RBS-R; Bodfish et al. 2000; Lams and Aman 2007) purport to be the only known tools specifically designed for the assessment of RRBs. The current version of the RBS-R (Bourreau et al. 2009) employs a descriptive approach that entails a professional providing behavioral ratings after the observation of the child in multiple contexts. This version has 35 items which are evaluated on a 5-point Likert scale. If the rater is not able to obtain enough information through observations, supplemental information may be obtained from a family member who knows the child well. Parents often fill out this scale as a questionnaire as well.

Interview Given that RRBs are not always present or readily observable during clinical or research assessments, obtaining information and descriptions about these behaviors through parent report is essential. As with social and communication skill impairments, ADI-R is used to gather information about the third domain of ASD through parent interview which includes 13 questions that are grouped in the “Interests and Behaviors” category. RRBs referenced include unusual preoccupations (interests that are odd or peculiar in quality); unusual attachments to objects; circumscribed interests that are unusual in intensity, circumscribed nature, nonsocial quality, and lack of progression over time; repetitive use of objects or interests in parts of objects (e.g., shaking strings, turning wheels and dials, opening and closing toy car doors); and compulsions or rituals (e.g., turning all lights off). The “Interests and Behaviors” category also includes questions about unusual sensory interests, sensitivity to everyday noises, and abnormal and predictable responses to specific sensory stimuli. Difficulties with changes in a child’s routine or environment, including resistance to minor changes in the environment (e.g., furniture moved, someone wears a hat who typically does not) are also captured. Finally, information about the presence of rapid, voluntary, and repetitive hand and finger mannerisms (e.g., twisting fingers, hand flapping) and other complex body mannerisms such as repetitively spinning in circles is collected.

Questionnaires There are few published questionnaires that focus solely on the assessment of repetitive and restricted behaviors in ASD. The Aberrant Behavior Checklist (ABC; Aman and Singh 1986) contains a stereotypic behavior subscale that inquires about the presence of repetitive hand, body or head movements, stereotyped repetitive movements, and odd and bizarre behaviors; however, it does not have a normative sample for children under 6 years of age. The Sensory Profile (Dunn 1999) assesses how well children aged 3 to 10 process sensory information in everyday situations and to what extent sensory factors impact functioning.

Other measures focus on all three domains characteristic of ASD including repetitive and restricted behaviors. Some of the more common questionnaires that provide information about the type, frequency, or severity of repetitive and restricted behaviors include: The Gilliam Autism Rating Scale which inquires about stereotyped behaviors; The PDD Behavior Inventory (PDDBI) which provides parent and teacher ratings of ritualistic/repetitive activities and resistance to change; and The Social Responsiveness Scale (SRS) which devotes questions to the presence of hand and complex body mannerisms, as well as the presence of rigidity, inflexibility, difficulties with coordination, and unusual sensory interests.

Experimental approaches The inconsistent, sporadic, and heterogeneous presentation of RRBs has made the assessment of behaviors in this domain challenging. While questionnaires, rating scales, and interviews have been widely used, experimental measures have also been developed to assess behaviors in this domain. The Interests Scale is a parent rating form that assesses the intensity, degree of interference, frequency of involvement, and involvement of others in interests for 39 typical childhood interests using multiple choice and open-ended questions (Turner-Brown et al. 2011). The Interview for Repetitive Behavior is a structured clinical interview to assess forms of repetitive behavior that are specific to a given individual based on items that are endorsed on the RBS-R (Turner-Brown et al. 2011). A number of behavioral coding systems have been used to quantify and assess repetitive behaviors in ASD (Gardenier et al. 2004; Symons et al. 2005). Goldman et al. (2009) coded the movements of children with ASD during 15-min videotaped play sessions. All movements were assigned to one of eight categories, but duration and amplitude of movements were unable to be scored because of challenges in establishing reliability concerning the start, end and intensity of the movements. Although the majority of experimental measures have consisted of behavioral coding schemes, advances in motion capture technology suggest new possibilities on the near horizon for methods to capture repetitive and restricted behaviors and interests in ASD.

Future Directions

There have been vast improvements in the assessment of ASD since Leo Kanner's first description of 11 individuals with autism and we can anticipate continued growth in our assessment and measurement of ASD. The measures used to assess the core features of ASD will continue to be refined and new measures will be developed just as our conceptualization and characterization of the core domains of impairment become more refined. A perfect example of this refinement is the movement away from conceptualizing ASD as a disorder marked by impairments in three domains to a disorder defined by impairments in two domains: social communication and restricted and repetitive interests and behaviors. As the focus of ASD transitions away from social and language deficits to social communication deficits, tools to assess the social use of language will continue to expand.

Additionally, as technologies become more widely available so will their use. Electrophysiology and eye-tracking approaches have helped to contribute to our understanding of the core impairments observed in ASD and increasingly more common in studies with young children. Functional and structural imaging paradigms have provided significant insight into the neurological contributions of the observed behaviors in ASD. These technologies will, no doubt, continue to enhance our understanding and contribute assessment paradigms to evaluate the skills and deficits in the core domains of ASD in young children.

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Measures Used to Screen and Diagnose ASD in Young Children

5

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Keywords
Screening · Diagnosis · Measurement

Symptoms of autism spectrum disorders (ASD), which are characterized by communication and socialization impairments and restricted and/or repetitive behaviors, typically present in early childhood (Matson et al. 2007a). With the early onset of symptoms, parents or caregivers may seek assessment and treatment for the child to address these abnormal behaviors (Matson and Smith 2008). As a result, in recent years, a large push has been initiated to develop reliable and valid assessment measures that can identify ASD in young children so appropriate treatment services can be implemented. Just one example of this effort is that some previous scales have been adapted to include both verbal and nonverbal versions since some young children may not have developed verbal language (Gotham et al. 2008). The early identification of ASD is especially important since literature supports early intervention as a predictor for better outcomes later in life (Ben Itzchak and Zachor 2011).

A variety of assessment instruments are available to clinicians ranging from general screening measures that broadly test for general developmental problems to more specific, thorough measures which can aid in distinguishing specific disorders on the autism spectrum (e.g., Pervasive developmental disorder- not otherwise specified [PDD-NOS] from autistic disorder). While many measures can assess symptoms of ASD in people across the lifespan, some instruments are specific and appropriate for examining ASD at a younger age. This specificity can be a strength because it allows for a developmental perspective to be taken in regard to behavior. Like ASD assessments for older children and adults, these instruments use a variety of methods and formats to glean information about the child's behavior. For example, some measures use yes/no questions that are asked to the parent or caregiver while others use structured observational sessions with the child during the assessment session.

In the current chapter, different methods of assessment are reviewed first, along with strengths and weaknesses of each method. Then, specific measures that assess for ASD and are appropriate for young children are reviewed beginning with broad screening instruments, followed by observational measures, structured parent/caregiver interviews, and informant-based behavior checklists. Only those measures appropriate for young children that have also received some attention in the empirical literature have been reviewed.

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Table 5.1 Assessment measures for autism spectrum disorders

Assessment measures	Age suitability	Administration time
Screening instruments		
Checklist for Autism in Toddlers (CHAT)	18 months and above	10–15 min
Modified Checklist for Autism in Toddlers (MCHAT)	16–30 months	5–10 min
Screening Tool for Autism in Two-Year-Olds (STAT)	24 to 35 months	15–20 min
Pervasive Developmental Disorders Screening Test- Second Edition (PDDST-II)	14 to 48 months	Varies based on form used
Social Communication Questionnaire (SCQ)	4 years and above (mental age of 2 years or older)	10 min
First Year Inventory (FYI)	12 months and above	Not reported
Observational measures		
Childhood autism rating scale (CARS)	2 years and above	30–45 min
Childhood autism rating scale- Second Edition (CARS2)	2 years and above	30–45 min
Pre-Linguistic Autism Diagnostic Observation Schedule (PL-ADOS)	6 years or younger	30 min
Autism Diagnostic Observation Scale-Generic (ADOS-G)	15 months or older with a mental age of 20 months or older	Approximately 30 min
Parent/caregiver structured interviews		
Autism Diagnostic Interview—Revised (ADI-R)	Mental age of 2 years or above	1.52 h
Diagnostic Interview for Social and Communication Disorders (DISCO)	Entire lifespan	2–4 h
Informant-based behavior checklists		
Gilliam Autism Rating Scale- Second Edition (GARS-2)	3–22 years	20 min
Pervasive Developmental Disorders in Mentally Retarded Persons (PDD-MRS)	2–55 years	10–20 min
Baby and Infant Screen for aUtistIc Traits (BISCUIT)	17–37 months	20–30 min

Additionally, measures specifically examining Asperger's syndrome will not be examined since this disorder is not typically diagnosed until later in childhood. Reviews of each measure include a general description of the instrument followed by a summary of known psychometric properties (i.e., reliability, validity, sensitivity, and specificity). Lastly, general conclusions and recommendations are discussed in regards to assessment of ASD in young children. Table 5.1 provides the names of all the measures reviewed as well as the appropriate age range for the test and the approximate amount of time needed to administer and score the measure.

Methods of Assessment

While there are many measures available to assess for ASD, these measures typically utilize one of three different methods to collect information about the child. These methods are clinician-rated observational measures, diagnostic interviews, and informant-based (typically parent or caregiver) behavior checklists. Each of these methods offers unique benefits while also having some weaknesses. Each of these methods is briefly discussed and the strengths and weaknesses of each are reviewed.

One popular form of assessment for ASD in young children is based on clinician ratings of the child's behavior. These observational measures' items represent behaviors that the clinician aims to elicit during the course of the observation/assessment session. Some of these measures can be highly structured and standardized with specific toys and objects being used during the assessment (Lord et al. 2002). One benefit of this assessment method is that it allows a clinician with training in developmental disabilities and who is familiar with developmental norms to make informed judgments based on those observations. This hopefully increases the validity of their ratings of behaviors and avoids some of the weaknesses of the other assessment methods that depend heavily upon parent or caregiver reports. On the other hand, the limited time during the observations means that certain low-frequency behaviors may not be elicited from the child though they occur outside of the assessment session. For example, repetitive behaviors and restricted interests may not be observed during the assessment but may be reported to occur by the parents. For this reason, some measures do not take into account repetitive behavior and restricted interests (Lord et al. 2002), and other measures allow observational information from the clinician to be supplemented with parent report (Schopler et al. 2010).

A second method of assessment that does utilize parents and caregivers as informants is the diagnostic interview. Diagnostic interviews, such as the Autism Diagnostic Interview-Revised (ADI-R; Rutter et al. 2003b), rely on informants to provide detailed information to structured interview questions. Unlike the informant-based behavior checklists (reviewed below) that obtain a number rating from the parents to represent the presence of specific behaviors, the structured diagnostic interviews allow the clinician to obtain detailed information about specific areas. This way, informants can elaborate on their responses, and if needed, the clinician can ask follow-up questions to acquire other important, related information. Another possible benefit of the diagnostic interview is that because more details are reported, this may allow the clinician to judge if parents are under- or overreporting. For example, if the parent reports "severe self-injurious behavior" but describes the behavior as only occurring a few times a week with no injury, then the clinician can take that into account and may consider that the parent is overreporting symptoms. The diagnostic interview is not without its weaknesses however. Compared to some other assessment methods (e.g., behavior checklists), the clinician requires more intensive training; sometime this includes attending specific trainings on administering one specific measure. This can become time-consuming and expensive for the clinician. Additionally, these interviews can require up to 2 h to administer whereas behavior checklists may only require 20 min (Table 5.1).

The last commonly used method to assess symptoms of ASD in children is the informant-based behavior checklist. These measures ask parents or caregivers of the child to answer items based on the child's behavior and symptoms, typically using a Likert scale for responding. Likert scales use ordinal ratings to determine the strength or level of the behavior in question. In the developmental disorders literature, using an informant is common as the individual being assessed often cannot report on these behaviors themselves. Benefits of behavior checklists include relatively short administration times with limited assistance needed from the clinician. Hence, only limited training, mostly on the scoring and interpretation of the instrument, is required. Furthermore, with this method, two informants can easily complete the questionnaire independently so that results may be compared and inconsistencies identified and addressed. Using multiple informants independently is not typically feasible with some other methods of assessment because of the length of time needed to administer the measure. While using a parent or caregiver to glean information about the child's symptoms provides the benefit of being able to sample behavior during a large time period, this method does have some limitations. As mentioned earlier, it may be difficult to determine if the information reported is an accurate representation of the child's behavior. It may be the case that parents over- or underreport symptoms. This may be due to a parent wanting a certain outcome from the assessment or may be from a lack of knowledge about what is considered typical behavior. Some assessments ask the informant to compare the child's behavior to typically developing peers which can be difficult if the informant has limited experience with other children.

Screening Instruments

Now that different methods for assessment of ASD have been discussed, special attention to one class of assessment tools is warranted, screening instruments. Often before a formal diagnostic assessment takes place, a screening measure is administered to parents or caregivers to determine if a child is at risk for ASD. Screening all children for ASD allows children who are not at risk (i.e., those that pass the screener) to avoid a more thorough, extensive assessment while also identifying children who are at risk (i.e., those who fail the screener) because they are exhibiting some symptoms of ASD. Within these screening instruments, there are two levels of assessments. Level 1 screeners are the broadest form and are typically administered to all children even if there is no current concern regarding development (e.g., during well-child visits at a pediatrician's office). These brief questionnaires are usually filled out by parents with little assistance from the clinician, though clinician observations are sometimes integrated into the screening process. Because these instruments are administered to such a wide range of children, the goal of these assessments is only to determine if the child meets the threshold for a developmental disability, not to differentiate ASD from other disorders. Some states have begun requiring that parents of all infants and toddlers who are at risk for ASD be offered these screenings as part of an effort to ensure early intervention for children with developmental disabilities.

In comparison to Level 1 screeners, Level 2 screening instruments offer a more specific look at ASD. While still broad in comparison to diagnostic tools, Level 2 screeners are used for those children who are already suspected of having a developmental disorder of some sort. These instruments often use observations by clinicians who are more familiar with the behaviors of typically developing children and of children with developmental disorders. Additionally, Level 2 screening instruments should be able to differentiate ASD from other developmental disorders such as language delay and intellectual disability. Unlike Level 1 screening tools, Level 2 screening tools do not depend solely on parent report which may be beneficial since parents may over- or underreport symptoms. On the other hand, screenings that rely more heavily on clinician observation may be inaccurate if behaviors during the observation are not representative of the child's typical behavior.

For both Level 1 and 2 screening instruments, as well as for the other assessment measures reviewed in this chapter, the usefulness of these measures is often evaluated based on their sensitivity and specificity. That is, how often does the tool accurately classify children as having ASD who go on to be diagnosed with ASD later in childhood (i.e., sensitivity)? And how often does the instrument identify children as not having ASD who do not receive later diagnoses (i.e., specificity)? False positives and false negatives on these screening instruments can have implications for the families. Children who pass the screener but truly do have the disorder (i.e., false negatives) will likely be delayed in receiving services, while children who fail the screener but do not have the disorder (i.e., false positives) will likely be subjected to additional testing which can be lengthy and expensive for the parents. In general, when discussing screening measures, it is more acceptable to have a higher level of false positives than false negatives. That is to say that it is better to unnecessarily complete a diagnostic work up for a child who does not have the disorder than to let a child with the disorder go unassessed and untreated.

Measures of ASD in Young Children

Having discussed the general methods of assessment available for screening and diagnosing ASD, specific measures under each method will now be reviewed. The focus of this review is on the most highly used and researched measures. Additionally, as Asperger's syndrome is not typically diagnosed until a later age, no measures specific to Asperger's syndrome will be discussed. Screening measures will be discussed first followed by observational measures, diagnostic interviews, and informant-based behavior checklists.

Screening Instruments

The Checklist for Autism in Toddlers The Checklist for Autism in Toddlers (CHAT; Baron-Cohen et al. 1992) is a Level 1 screening tool which can be easily administered by a pediatrician or other clinician with minimal training. Composed of two parts, the CHAT requires 10–15 min to administer. Part 1 of the CHAT includes nine items that are answered by the parent during a brief interview. Five of these items are key items. If all of these items are failed, the presence of an ASD is likely. A subset of these items (e.g., assessing protodeclarative pointing) indicates a moderate risk for ASD if failed. Aside from these key items, the other items are meant to aid in differentiating among different developmental disorders. The second portion of the CHAT is an observation that is made up of five behaviors suggestive of developmental disorders that is completed by the clinician.

In examining the usefulness of the CHAT, the instrument was administered to 50 18-month-old children in order to determine which items were normally passed by typically developing children (Baron-Cohen et al. 1992). Then, the CHAT was administered to 41 children who had siblings with ASD hence placing these children at a higher risk. The CHAT accurately identified all four of the children in the sample who went on to receive later diagnoses of ASD.

Following this study, a larger sample of 16,000 18-month-olds from England was obtained to examine the usefulness of three key items (i.e., "protodeclarative pointing," "gaze-monitoring," and "pretend play") in identifying children who go on to be diagnosed with ASD (Baron-Cohen et al. 1996). Of the sample, 12 children failed all three items and ten went on to receive diagnoses of ASD which resulted in a true positive rate of 83.3 % and a false positive rate of 16.6 %. For children who failed protodeclarative pointing and/or pretend play items, 68.2 % received a diagnosis of language delay, but none were diagnosed with ASD. Overall, these findings indicate the three key items adequately identify children who go on to be diagnosed with ASD.

Baird et al. (2000) examined the effectiveness of the CHAT with a 6-year follow-up study using a sample of 16, 235 children. Nineteen children were identified as having ASD at the first administration of the CHAT. At follow-up using the children's current diagnoses, 50 children had received a diagnosis of ASD. This resulted in a specificity of 98 %, but a low sensitivity of 38 %. When the CHAT was readministered at 19 months of age, the sensitivity was once again low at 20 %, but the specificity remained high at 100 % with the overall positive predictive value being 75 %. These findings highlight the weakness of the CHAT in terms of its sensitivity, though sensitivity is improved in high versus moderate risk samples of children. In addition, the inability of the CHAT to accurately assess children with PDD-NOS as opposed to autistic disorder (AD) has been highlighted as a weakness (Robins et al. 2001; Scrambler et al. 2001).

The Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al. 2001) In response to some of the criticisms and weaknesses of the CHAT, a modified version was created named the Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al. 2001). The changes seen in the M-CHAT include an extended age range, now appropriate for children 16–30 months, and the elimination of the observational component (Dumont-Matthieu and Fein 2005). This was in an effort to make the M-CHAT usable across a variety of cultures in which the observational component was not as feasible. Because of the removal of the observational aspect, the parent-report questions are broader to sample a wider range of behaviors. The 23 items, six of which are critical items, are answered in a yes/no format. The full measure requires about 5 min to administer. The screener is failed if the child fails two of the critical items or three of the 23 items.

Several researchers have examined the psychometrics of the M-CHAT. Robins et al. (2001) used a sample of 1,122 children aged 18–24 months during well-baby checkups and 171 children with previously diagnosed DSM-IV disorders. In terms of reliability, internal consistency was 0.85 for all items and 0.83 for critical items. Further investigation revealed a positive predictive power of 0.80, a negative predictive power of 0.99, a sensitivity of 0.87, and a specificity of 0.99. The M-CHAT attempted to strengthen its specificity by decreasing the cutoff score for a positive screen when compared to the CHAT (Coonrod and Stone 2005; Robins et al. 2001). A limitation of this study, however, was that diagnoses were not confirmed with follow-up evaluations. As a result, conclusions from this study should be interpreted with caution. Other studies examining the psychometrics of the M-CHAT have revealed fair to excellent internal consistency, 0.77 for critical items and 0.92 for total scores; however, specificity was still found to be lacking, 0.43 and 0.27, respectively (Eaves et al. 2006b). As was the case with the CHAT, the M-CHAT should be used with the understanding that the likelihood for a false positive is relatively high and a thorough diagnostic work up should be completed to confirm diagnoses.

While the M-CHAT is commonly used in English-speaking countries, it has also been translated into other languages and used across the world. As of 2011, the M-CHAT had been translated into 28 different languages (Robins 2011). One example of these translations and adaptations is the CHAT-23 which was translated and adapted for Chinese populations (Wong et al. 2004). In order to adapt the scale, the authors used a 4-point Likert scale as opposed to the original yes/no format and also included the five observational measures from the original CHAT. As with the original measure, the scoring has critical items and noncritical items. The CHAT-23 is considered to be failed when two of the seven critical items or six of the 23 total items are failed. The authors proposed that the questionnaire portion of the CHAT-23 be used as a first tier assessment, while the observational component should only be given if the first portion is failed. As with any translated measure, the psychometrics of the scale need to be reestablished in the new language. The authors reported a sensitivity of 0.74–0.93, a specificity of 0.77–0.91, and a positive predictive value of 0.74–0.85 with the new version of the measure.

Screening Tool for Autism in Two-Year-Olds The Screening Tool for Autism in Two-Year-Olds (STAT; Stone and Ousley 1997) is a Level 2 screening tool to be administered by health-care workers or other service providers. This 12-item measure is designed for children aged 24–35 months and is to be completed during play interactions between the child and the clinician. The entire measure requires 15–20 min to complete. Within these 12 items, there are several domains of behavior examined: two regarding play, four examining imitation, four regarding directing-attention items, and two unscored items of response to requests. Each item is scored based on if the child completes the goal target behavior, and each of the areas (i.e., play, imitation, and attention) has its own cutoff score. If two of the three scored areas are failed, the total screen is considered to be failed.

Limited studies have examined the psychometrics of the STAT. Based on the scoring criteria proposed by the authors, the sensitivity was 0.83 while the specificity was 0.86 (Stone et al. 2000). However, other studies using different scoring criteria found improved sensitivity and specificity, 0.92 and 0.85, respectively (Stone et al. 2004). Stone et al. (2008) also examined the STAT to determine if it would be a useful screening instrument for children aged 12–23 months. Findings indicated promising sensitivity, 0.95, and specificity, 0.73. The positive predictive value was somewhat low at 0.56 while the negative predictive value was 0.97. Further investigation revealed that the sensitivity and specificity were especially lower for children aged 12–13 months indicating this measure should be used with caution for children this young. Additionally, studies examining the reliability and validity of this scale are lacking and should be conducted to support the use of the measure in clinical settings.

Pervasive Developmental Disorders Screening Test-Second Edition The Pervasive Developmental Disorders Screening Test-Second Edition (PDDST-II; Siegel 2004) is a screening tool that differs from some of the previously discussed measures in that it can function as a Level 1 or Level 2 measure. This instrument, appropriate for children aged 12–48 months, has three forms that are administered in different stages. The three forms are Primary Care Screener (23 items), Developmental Clinic Screener (14 items), Autism Clinic Severity Screener (12 items), and they range from a general screening tool that detects any developmental problem to the higher-level forms that differentiate among different disorders on the ASD spectrum. This measure was standardized with children who had other neurodevelopmental disorders (e.g., ADHD, ID, language disorders) as well as children with ASD. By using this sample to norm the PDDST-II, ASD can be differentiated from these other disorders common in early childhood. For the first stage of the assessment, items are scored on a three-point scale representing how often the behaviors occur with total scores of five or greater indicating that more extensive screening should be completed with Stages 2 and 3 of the PDDST-II.

Once again, limited information is available on the psychometrics of this instrument. There are some promising data on Stage 1 (i.e., Primary Care Screener) with a sensitivity of 0.92 and a specificity of 0.91; however, sensitivity and specificity are not as promising for Stages 2 and 3, with sensitivities of 0.73 and 0.58 and specificities of 0.49 and 0.60, respectively. Based on this information, the PDDST-II does not seem to have adequate power to differentiate among different ASD. While the stage structure of this measure seems good in theory, further research is needed to support the utility of this measure.

Social Communication Questionnaire The Social Communication Questionnaire (SCQ; Rutter et al. 2003b) is a screening tool that was developed using items from the ADI-R (Rutter et al. 2003b), which is reviewed in depth in the diagnostic interview section. Previously named the Autism Screening Questionnaire (ASQ), the SCQ is a 40-item parent-report questionnaire that requires 10 min to administer and can be used to assess children as young as 4 years with a mental age of 2 years. Like the ADI-R, the SCQ has three subscales: social development and play, communication, and repetitive and restricted behaviors. There are also different forms of the SCQ including the lifetime form that takes all developmental history into account and the current form that only examines behavior over the past 3 months. A score of 15 or above indicates risk for ASD and the need for a more comprehensive assessment. Using this cutoff, the SCQ is adequately able to discriminate between ASD and non-ASD across all cognitive levels. While 15 is the cutoff point determined by Berument, Rutter, Lord, Pickles, and Bailey, other researchers have suggested that different cut points may be useful depending on the sample and purpose of the assessment (e.g., research versus clinical purposes; Lee et al. 2007).

The psychometrics of this measure seem promising overall. Not surprisingly, the developers of the scale found that the SCQ correlates highly with the ADI-R (Berument et al. 1999); however, due to methodological flaws the results must be interpreted with caution. Berument et al. (1999) also examined the sensitivity and specificity between ASD and non-ASD which was acceptable with a sensitivity of 0.85 and a specificity of 0.75 (Berument et al. 1999). Using both clinical and general population samples with ASD, Chandler et al. (2007) found similar results, though it should be noted that an older sample of children was used. In this study, when differentiating between ASD and non-ASD, sensitivity was 0.88 and specificity was 0.72. These statistics remained high even when differentiating AD from non-AD (all other ASD and non-ASD; sensitivity 0.90, specificity 0.86). On the other hand, other studies examining these indicators were not quite as strong with a reduced sensitivity of 0.71 (Eaves et al. 2006b) and reduced specificity of 0.54 (Eaves et al. 2006b). Overall, this measure seems to have some utility as a screening measure though other psychometrics, such as reliability, need to be evaluated in more depth.

First Year Inventory The First Year Inventory (FYI; Reznick et al. 2007) is a relatively new screening tool that aims to assess children beginning at the age of 12 months. This measure is meant to identify children who are at a risk for atypical development, but there is a specific focus on examining ASD characteristics. The items for the FYI were created from a pool of items developed based on extensive literature reviews and current theories regarding ASD. While the two main factors of this scale are social-communication and sensory-regulatory functions, there are also some items which target general developmental problems and associated problems with autism. The whole measure includes 63 items; the first group of items are scored on a 4-point Likert scale (1 = "Never," 2 = "Seldom," 3 = "Sometimes," and 4 = "Often") while the second group of items are multiple choice. While limited research has been conducted on the FYI, the pilot study, which used mailings to families, suggests that the measure is easy to use and may be useful to pediatricians as a screening tool. Some preliminary data also suggest the FYI can discriminate among children with ASD, other developmental disorders, and typical development (Watson et al. 2007). However, the FYI is typically used more often in research, and the measure is also longer than most other screening measures which may limit its utility in clinical settings.

Diagnostic Measures

Having reviewed the common measures used to screen for ASD in young children, the discussion now moves to those measures used during more comprehensive evaluations. These measures, in some cases, can reliably distinguish among different ASD (Mahoney et al. 1998). As mentioned above, several methods and types of these assessments exist including observational measures, structured parent/caregiver interviews, and parent/caregiver-report behavior checklists. Specific measures within each of these categories are reviewed.

Observational measures Observations by the clinician can provide invaluable information during the assessment process. Because these clinicians have specific training and a background in ASD, they know what behaviors to look for and try to elicit during the assessment. With the use of structured observational assessments, this process can be standardized and scores can be assigned that can then be interpreted based on norms. Some of the more commonly used observational scales are reviewed here including the Childhood Autism Rating Scale (CARS; Schopler et al. 1988), the Childhood Autism Rating Scale-Second Edition (CARS2; Schopler et al. 2010), the Pre-Linguistic Autism diagnostic Observation Schedule (PL-ADOS; DiLavore et al. 1995), and the Autism Diagnostic Observation Scale-Generic (ADOS-G; Lord et al. 2002).

Childhood Autism Rating Scale The purpose of the CARS (Schopler et al. 1988) is to differentiate ASD from other developmental disorders in children 2 years and above. The information in the CARS is primarily obtained through the clinician's interaction with and observation of the child within session, but this information can be supplemented with parent or caregiver reports regarding the child's behavior. The 15 items are considered subscales and examine the following behavior domains: relating to people, imitation, emotional response, taste-smell-touch response and use, fear or nervousness, verbal communication, nonverbal communication, activity level, level and consistency of intellectual response, and general impressions. It should be noted that these items are not based on any classification system such as the *Diagnostic and Statistical Manual of Mental Disorders-Text Revision-4th Edition* (*DSM-IV-TR;* American Psychiatric Association (APA) 2000) or the *International classification of diseases-10th Edition* (*ICD-10*; World Health Organization (WHO) 1992). Each of the items is rated by the clinician on a 4-point scale ranging from 1 ("within normal limits") to 4 ("severely abnormal"), and half point scores are allowed. Because the clinician needs to compare the target child's behaviors to same-age peers, it is important that the clinician be familiar with developmental norms of behavior. Based on the total score of the 15 items, the child will fall in an ASD range non-autistic (scores below 30), mild to moderate autistic (scores between 30 and 36.5), and moderate to severe autistic (scores between 37 and 60). The measure requires 30–45 min to administer and score and is relatively easy to administer across a variety of settings (e.g., home and classroom settings).

Since its inception, several researchers have examined the psychometrics of the CARS. The creators of the CARS found good evidence for several different types of reliability. Cronbach's alpha was 0.94 for internal consistency, while test-retest reliability over a period of 1 year was 0.88. Inter-rater reliability was 0.71 for the whole scale with a range from 0.55 to 0.93 when examining each subscale individually. Validity was also examined with criterion validity ranging from 0.80 to 0.84 when compared with expert clinical ratings. Additionally, validity was found to be consistent independent of how and in what setting information was obtained. That is, observations in classroom settings, information provided from parent interview, and information gleaned from behavioral history reviews resulted in similar outcomes. Saemundsen et al. (2003) also examined convergent validity of the CARS with the ADI-R (Rutter et al. 2003b). They found overall convergence with significant correlations between the total ADI-R score and the subscales of the CARS that ranged from 0.60 to 0.81. The CARS, however, correctly classified more children accurately compared to the ADI-R, and agreement between the two methods was only 66.7%. In terms of the ability of the CARS to correctly classify children with ASD, children were correctly identified as having ASD 87% of the time, while they were misclassified as not having the disorder 14% of the time, and misclassified as having ASD 11% of the time (Schopler et al. 1988). Overall, the CARS has adequate psychometrics and has proven to be valuable in clinical settings.

Childhood Autism Rating Scale- Second Edition The CARS2 (Schopler et al. 2010) is a recently released new version of the original measure which has been changed to address some of the shortcomings of the earlier version. Some of the changes include the increased usefulness for individuals at the higher-functioning end of the spectrum (i.e., those with better language and cognitive abilities), integration of diagnostic information, assessment of functional capabilities, provision of feedback to parents, and integration of treatment designs. The new measure is still appropriate for children 2 years and above, and the CARS2 is scored in the same fashion as the CARS (Schopler et al. 1988). Unlike the CARS which has only one form, the CARS2 has three. The first form is the Standard Version Rating Booklet (CARS2-ST) which is most similar to the original CARS. This form is most appropriate for children under 6 years of age and children with more severe language and cognitive impairments. The second form is the High-Functioning Version Rating Booklet (CARS2-HF) which should be used for individuals aged 6 years and above and those people with IQ scores above 80. The items on both of these forms are similar to the first version of the CARS, but on the CARS2-HF some items have been adapted to more accurately reflect characteristics typical of those who are higher functioning. For example, the item that examines imitation on the CARS2-SF is worded on the CARS2-HF to reflect social-emotional understanding which is more appropriate for higher-functioning children. The third form of the CARS2 is an unscored parent questionnaire which can be used to obtain parent reports of behavior to supplement clinician observations.

Psychometrics of the new version of the CARS2 is limited at this point. Examination of reliability from the authors indicates high internal consistency and inter-rater reliability (Schopler et al. 2010). The ability of the CARS2-HF to identify those with and without ASD is also promising with sensitivity and specificity of 0.81 and 0.87, respectively. Further replication of these results from other researchers is needed to confirm the reportedly strong psychometric properties of the CARS2.

Pre-Linguistic Autism Diagnostic Observation Schedule The PL-ADOS (DiLavore et al. 1995) is an adaption of the original ADOS (Lord et al. 1989). This new version of the measure is more applicable in clinical settings (i.e., requires only 30 min to complete and can be administered in a less structured environment) and can be used with younger children (6 years and younger) who have no verbal language and are suspected of having ASD. Similar to its predecessor, the PL-ADOS is an observational measure that examines play, interaction, and social communication. The structure of this measure is based on 12 activities that obtain information on behaviors that are typically absent or abnormal in children with ASD.

These activities include independent use of toys, engagement with parents, repeats own action when imitated, responds to joint attention, anticipates routine with objects, initiates joint attention, anticipates a social routine, requests, functional/symbolic imitation, takes turns, imitates during party, requests during snack, responds to name, smiles socially, responds to another's distress, separates from mother, and reunites with mother. From these 12 items, scores of 0 (indicating no abnormality), 1 (indicating a response that is not typical but not indicative of an ASD), or 2 (indicating a response consistent with autism) are given in the following areas: communication, reciprocal social interaction, play, stereotyped behavior and restricted interests, other abnormal behavior, and an overall autism clinical rating.

Based on the items that were able to differentiate those children who were nonverbal with ASD and those who were nonverbal with another developmental disorder, a scoring algorithm was developed. Using this algorithm, meaningful discriminations were made between young children with ASD and children with non-ASD developmental delays (DiLavore et al. 1995). In addition, inter-rater reliability has been evaluated for each of the core areas: 0.71–0.83 for communication, 0.60–0.94 for reciprocal social interaction, 0.78–1.0 for play, 0.60–0.92 for stereotyped behavior and restricted interests, 0.65–0.79 for other abnormal behaviors, and lastly, 0.86 for the overall autism rating (DiLavore et al. 1995). While the PL-ADOS improved upon the ADOS by being able to assess children with no verbal abilities, children with present but very limited verbal abilities were still not appropriately assessed with either measure. This led to the development of the next measure discussed, the ADOS-G.

Autism Diagnostic Observation Scale-Generic The ADOS-G (Lord et al. 2002) is the third observational measure to come after the ADOS and PL-ADOS. The ADOS-G is a semi-structured, standardized observational measure that was developed to be used with the ADI (LeCouteur et al. 1989). In order to ensure standardization of administration procedures across assessors, more extensive training is required to administer this measure. Changes to the ADOS-G from the preexisting measures include a lower age range (i.e., can be used with children aged 15 months or older with a mental age of 20 months or older) as well as the use of four different modules which cover a variety of developmental and language levels. The module administered is determined by the child's individual abilities. Most modules have 10–14 activities that use standardized materials and can be completed in approximately 30 min. Module 1 is meant for preverbal children who have very limited speech (i.e., at the most one word); module 2 is for children who have some language but do not have fluent speech (i.e., age equivalent to that of a typically developing child of 30 months); module 3 is for children with fluent speech; and module 4 is for adolescents and adults with fluent speech. Fluent speech in modules 3 and 4 is defined as an age equivalent of at least 48 months. The child is rated on specific behaviors including things like use of gestures, joint attention, and unusual eye contact. The use of different modules allows for children with similar verbal abilities to be compared which controls for this variation in these skills.

At the conclusion of the observation, an algorithm is used to determine if cutoff criteria are met for the two main areas, communication and social interaction, as well as a total score on the social interaction-communication score. Each activity or behavior is rated on a three-point scale: 0 (no evidence of abnormality related to autism) to 2 (definite evidence). While scores can be given for the restricted and repetitive behavior domain, this data is not required to meet criteria as these types of behavior may not be exhibited in the 30 min of the typical observation.

Psychometrics on the ADOS-G seem to support the utility of this measure (Lord et al. 2000). Depending on what algorithm is being used, test-retest reliability ranged from 0.73 to 0.78 and inter-rater reliability was excellent ranging from 0.84 to 0.93. Internal consistency ranged from 0.74 to 0.94 on each domain (collapsed across algorithms). In terms of sensitivity and specificity, while the ADOS-G is adequately able to discriminate between ASD and non-ASD (sensitivity = 0.95 and specificity = 0.92), the measure is not as capable of discriminating among different disorders on the spectrum.

Parent/caregiver structured interviews When working with young children, it is often the case that clinicians need to rely on information from the parent or caregiver as the child is not typically able to report on his/her own behaviors. Additionally, while the observational measures just discussed are useful, some target behaviors may not be exhibited during the assessment session though they occur at other times. By gleaning information from parents, a wide range of behavior is able to be inquired about. More specifically, structured interviews allow clinicians to ask a predetermined set of questions that can then be scored and interpreted to aid in the diagnosis of ASD in young children. Two of the more commonly used structured interviews that can assess for ASD in young children, the ADI-R (Rutter et al. 2003b) and the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing et al. 2002) are reviewed below.

Autism Diagnostic Interview-Revised The ADI-R (Rutter et al. 2003b) is a structured interview appropriate for children with a mental age of 2 years and above, and it was adapted from the original ADI (Lord et al. 1989). In comparison to the ADI, the ADI-R is appropriate for younger children and is better at differentiating ASD for other mental problems, though it does require more time to complete than the earlier version (i.e., one and half to two and a half hours for the ADI-R). The ADI-R is also meant to be used in conjunction with the ADOS, ADOS-G, or PL-ADOS. While the observational measure targets what behaviors are exhibited in session with the clinician, the ADI-R allows information about behavior from early development to also be obtained and considered.

The ADI-R is composed of 93 items which glean information in four domains: qualities of reciprocal interaction; communication and language; restricted, repetitive, stereotyped behaviors and interests; and age of onset of symptoms. More broadly, there are eight content areas which parents and caregivers are asked to report on including child's background (e.g., family, education, and previous diagnoses), overview of child's behavior, early development and developmental milestones, language acquisition or regression, current language and communication functioning, social development and play, interests and behaviors, and other clinically relevant behaviors (e.g., aggression or epilepsy). Items are presented and worded in a way that enhances a respondent's likelihood of reporting behaviors from early development accurately. For each response, the interviewer codes the response accordingly, and these scores are then entered into the appropriate algorithm (i.e., diagnostic algorithm or current behavior algorithm) which have all been extensively examined. The diagnostic algorithm is used for determining if the child meets criteria for AD based on the *DSM-IV-TR* (APA 2000) and *ICD-10* (WHO 1992). Scores need to meet the cutoff criteria in each area to warrant a diagnosis of autism: social impairment = 10, communication and language = 8 (verbal) and 7 (nonverbal), restricted and repetitive interests or behaviors = 3, and age of onset = 1.

Because the ADI-R is widely used in research, its developers as well as other researchers have examined the psychometric properties of this instrument. Lord et al. (1994) found test-retest and inter-rater reliability ranged from 0.62 to 0.89. Internal consistency in each of the domains was also high: 0.95 (social), 0.69 (restricted and repetitive behaviors), and 0.84 (communication). Investigations of the reliability by other researchers have found lower, yet still acceptable levels of consistency (Lecavalier et al. 2006). In terms of sensitivity and specificity Lord et al. (1994) found agreements of 0.64–0.89 for social interaction, 0.69–0.89 for communication, and 0.63–0.86 for restricted and repetitive behaviors. Other researchers have found similar results (Cox et al. 1999). The ADI-R was able to discriminate between those with AD and those with other language disorders, with the former group scoring higher when compared to the latter group (Mildenberger et al. 2001). Similarly, in terms of differentiating ASD from other developmental disorders, sensitivity ranged from 0.86 to 1.00

and specificity ranged from 0.75 to 0.96 (Lord et al. 1997). Overall, the ADI-R seems to be psychometrically sound. This strength, however, needs to be weighed against the large amount of time that is required to administer the measure, which does not always make it feasible in clinical settings. In addition, the ADI-R is not designed to discriminate among different disorders on the autism spectrum as cutoffs are based on full criteria for AD.

Diagnostic Interview for Social and Communication Disorders The DISCO (Wing et al. 2002), originally developed by Wing and Gould, is a semi-structured interview that collects developmental information on a variety of behaviors and skills as reported by parents and caregivers who are familiar with the child. The DISCO is versatile in that it can be used across the lifespan for people with all levels of functioning. This measure can be used to determine a diagnostic classification, but can also provide the clinician with pertinent developmental information which can be useful in treatment planning. The DISCO is also used fairly commonly in research. The items on this measure were obtained through an examination of diagnostic criteria for ASD, clinical experience, and developmental items from measures of adaptive functioning. Items regarding the core symptom areas of ASD are coded appropriately based on the response in a similar manner as what was described with the ADI-R. Additionally, information is gleaned regarding ages of developmental milestones and details are obtained in the areas of self-care, independence, visuospatial abilities, untypical responses to sensory stimuli, motor stereotypies, catatonia, psychiatric disorders, forensic problems, and difficulties related to sexual behavior.

A number of scoring algorithms have been developed in research for this measure (Leekam et al. 2002), and the number of items administered can vary based on what algorithm is used. One commonly used algorithm is based on the ASD definitions and criteria provided by the ICD-10 (WHO 1992) and another is based on Wing and Gould's ASD definition. Similar to the ADI-R, the DISCO can be used to examine both retrospective and current behavior depending on the purpose of the assessment. Using the ICD-10-based algorithm, inter-rater reliability was found to be 0.75 for a sample of school-aged children and a sample of preschool-aged children (Wing et al. 2002). A Swedish version of the DISCO has also been evaluated for its reliability and validity. Inter-rater reliability was found to exceed 0.90 for items used in the algorithm and the DISCO was also found to have excellent convergent validity with the ADI-R (Nygren et al. 2009).

While the DISCO does cover a large amount of information, it does require 2–4 h to administer which makes it difficult to use in clinical settings where time can be limited. In addition, as with all assessment measures for ASD, it should not be used as the sole measure to diagnose. The authors of the scale also recommend a neuropsychological assessment and a review of previous assessments and reports before determining a diagnosis.

Informant-based behavior checklists Like structured interviews, behavior checklists are another way for clinicians to obtain information about a child's symptoms from a parent or caregiver who knows the child well. While interviews can be time-consuming, behavior checklists offer the benefit of brevity, usually requiring 15–20 min to complete and score. These measures can also be easily administered to different informants separately, such as a mother and a father, so that consistency in the reporting of behaviors can be compared. Three of the more commonly used informant-based checklists are reviewed here: the Gilliam Autism Rating Scale-Second Edition (GARS-2; Gilliam 2006), the Pervasive Developmental Disorders in Mentally Retarded Persons (PDD-MRS; Kraijer 1997), and the Baby and Infant Screen for aUtistIc Traits (BISCUIT; Matson et al. 2007a).

Gilliam Autism Rating Scale-Second Edition The GARS-2 (Gilliam 2006) is a behavior checklist used to indicate the severity of autism to allow for treatment planning and also to distinguish between children with general behavior problems and those with ASD. Appropriate for individuals aged 3–22 years, the 42 items that make up the scale are scored based on parent-reported behaviors but can also incorporate observations by the clinician during the course of the assessment. The main section of the assessment contains three subscales: stereotyped behaviors, communication, and social interaction. Each item is scored on a 4-point Likert scale ranging from 0 (never observed) to 3 (frequently observed). After hand scoring the measure, the child receives an overall autism index (AI) and subscale scores with cutoffs to indicate the level of autism symptoms. The GARS-2 also includes a short, structured parent interview to obtain supplemental information. This interview includes 25, yes/no format, questions that inquire about abnormalities or delays in the areas of social interaction, language used in social communication, and symbolic or imaginative play. The clinician administering the measure should have general training and familiarity with ASD, as well as training in test administration and score interpretation, but does not require any other specific training for using the GARS-2.

The GARS-2 was normed on a sample of 1,107 persons based on reports from parents, caregivers, and teachers. Unfortunately, diagnoses were not confirmed by an established method of assessment so psychometric findings based on this sample should be interpreted with caution. In terms of reliability, internal consistency was found to be 0.94 for the whole scale with coefficients of 0.84, 0.86, and 0.88, for the stereotyped behavior, communication, and social interaction subscales, respectively. Test-retest reliability was adequate with reliability coefficients of 0.84 for the AI and ranging from 0.64 to 0.83 for the subscales. Concurrent validity was examined in comparison to the Autism Behavior Checklist ($r=.62$). In both higher-functioning and lower-functioning individuals, the GARS-2 was able to discriminate between those with ASD and those with behavior problems only. The sensitivity of the GARS-2 ranged from 0.84 to 1.0, the specificity ranged from 0.84 to 0.87, and positive predictive power ranged from 0.84 to 0.85. However, as stated above, methodological flaws in how true diagnoses were determined limits the conclusions of these psychometrics.

Pervasive Developmental Disorders in Mentally Retarded Persons The PDD-MRS (Kraijer 1997) is a parent/caregiver-based report measure which aims to assess ASD in persons with intellectual disabilities, aged 2–55 years. The 12-item instrument was created based on a literature review, diagnostic criteria (i.e., *DSM* and *ICD-10*), and existing scales; the PDD-MRS requires approximately 10–20 min to administer. When answering items, parents and caregivers should reference behaviors of the child for the past 2–6 months. Clinicians can also supplement information supplied from the informant with information based on their own observations of the child, though this is not necessary. Due to some of the items being weighted, with weights ranging from 1 to 3, the total possible score in the PDD-MRS is 19. Based on the total score, there are three descriptive categories which the child may fall under: scores of 6 or less indicate non-PDD, scores of 7–9 indicate doubtful PDD/non-PDD, and scores of 10 or greater indicate PDD. This measure can be easily administered by a variety of clinicians in the mental health field and requires a familiarity with ASD and intellectual disabilities but no other formal training. While the original version of the PDD-MRS was developed in the Netherlands with a Dutch-speaking population, the measure has also been translated into German and Italian.

The psychometric properties of the PDD-MRS have been investigated and thus far seem promising. The internal consistency was investigated using two different samples, one sample of persons with functional speech and one sample of persons without functional speech. Cronbach's alpha was found to be 0.86 and 0.81 respectively for these samples. Inter-rater reliability was also found to be adequate ranging from 0.83 to 0.89. Lastly, in terms of reliability, test-retest consistency was 0.81–0.86 for a period of 6 months and 0.72 over a period of 14 years. Concurrent validity was examined by comparing diagnoses given by psychologists or medical experts and the diagnostic range as determined by the PDD-MRS. The PDD-MRS was found to correctly identify 94.4 % of those people with ASD and 92.7 % of those people without ASD. While overall the psychometrics of the PDD-MRS support the utility of the measure, the measure can be used in both children and adults. It would be useful to examine the psychometric properties of the instrument in a younger sample specifically to ensure its use is appropriate for young children.

Baby and Infant Screen for aUtistIc Traits The BISCUIT (Matson et al. 2007a) is the third of the informant-based behavior checklists reviewed. This measure differs from the other two checklists in that it is specific to young children aged 17–37 months. In addition, the BISCUIT includes three parts. Part 1, similar to the other measure discussed, is the diagnostic section which obtains information on the core symptom areas of ASD. Factor analysis supports a three-factor structure (i.e., socialization/nonverbal communication, repetitive behavior/restricted interests, and communication) that were determined via exploratory factor analysis (Matson et al. 2010). Parts 2 and 3, however, focus on areas related to ASD that are not covered in the other informant report instruments. Part 2 gleans information on comorbid symptoms that are commonly seen in young children with ASD (e.g., tic disorders, ADHD, obsessive compulsive disorder, and specific phobia), and Part 3 addresses the presence of challenging behaviors (e.g., self-injury, aggression, disruption, and repetitive behaviors). The three parts together are advantageous since comorbid symptoms and challenging behaviors are common in young children with ASD and these areas should be addressed during assessment and treatment. This measure can be used as a screening tool but also has sound psychometric properties which make it appropriate as a diagnostic tool. The BISCUIT can also be used for treatment monitoring though more research on its sensitivity to treatment outcomes needs to be conducted. The measure requires approximately 20–30 min to administer and score.

Items for all parts of the BISCUIT were developed based on a comprehensive review of the literature, review of the *DSM-IV-TR* (APA 2000) and the *ICD-10* (WHO 1992) and consultation with a clinician who has expertise with this population and over 35 years of experience in the field of developmental disabilities. Part 1 has 62 items that are answered on a three-point Likert scale: 0 (not different; no impairment), 1 (somewhat different; mild impairment), or 2 (very different; severe impairment). An appendix provides examples of age-appropriate behaviors for each item as well as examples of atypical behaviors for each item. Parts 2 and 3 of the BISCUIT have 57 and 15 items respectively and are also answered on a similar 0–2 rating scale based on the severity of and impairment created by each behavior. Based on the responses from Part 1 of the instrument, a total score is obtained. Using a sample of 1,007 infants and toddlers, cutoff scores based on optimal sensitivity and specificity were determined with a score of 17 differentiating between atypical development and PDD-NOS and a score of 39 differentiating between PDD-NOS and AD (Matson et al. 2009). Those administering the measure should hold at least a bachelor's degree in the health services field and be familiar with ASD as well as be familiar with test administration and interpretation.

The reliability and validity, as well as sensitivity and specificity, have been researched for the BISCUIT. The internal consistency for the entire measure was 0.97. For each of the subscales, socialization/nonverbal communication, repetitive behavior/restricted interests, and communication, Cronbach's alphas were 0.93, 0.91, and 0.82, respectively (Matson et al. 2009). In regard to validity, convergent validity was 0.80 with the M-CHAT (Robins 2011) and −0.50 with the personal-social domain of the Battelle Developmental Inventory-Second Edition (BDI-2; Newborg 2005). Divergent validity with the adaptive domain of the BDI-2 was also demonstrated at −0.19 (Matson et al. 2011). Based on the cutoff scores described above, sensitivity and specificity were 0.93 and 0.86, respectively with an overall correct classification rate of 0.88. Overall, along with strong psychometrics, the BISCUIT offers the benefits of being designed specifically for young children and offers the benefits of collecting additional information on related problem areas for children with ASD.

Conclusions and Recommendations

As can be seen by the review of measures available to screen and diagnose ASD in young children, clinicians have a variety of options when conducting an assessment. Clinicians then have the task of determining the best way to assess the child. Here, several recommendations for how to assess ASD in young children are offered.

The assessment of ASD in young children needs to be as comprehensive as possible. In some cases, the child may have screened positive on one of the screening measures discussed and now requires a more thorough assessment. To begin this assessment, the clinician should conduct a general interview with the parent to obtain information on the child's developmental history (e.g., developmental milestones) and medical history. In some cases, due to medical problems or other factors, a multidisciplinary approach to assessment is preferred. This may include input from other professionals such as medical doctors, occupational therapists, audiologists, etc. The general information gathered at the beginning of an assessment will also inform the clinician about what the best assessment tools will be for the specific child (e.g., does the child have verbal abilities?). Once some general information is acquired about the child, the use of formal assessment instruments can begin.

As highlighted above, each of the methods of assessment (e.g., observations and informant reports), as well as the individual instruments, possess their own strengths and weaknesses. Because of this, clinicians should use multiple methods in making a diagnosis. Instead, a multi-method, multi-informant approach to assessment is recommended. A multi-method approach means that the assessment should include measures that incorporate the clinician's observations, such as the CARS2, as well as measures that rely more heavily on informant's responses, such as the BISCUIT. Additionally, throughout the entire assessment period, the clinician should be making informal observations of the child's behavior, in addition to the observations that occur during structured observational assessments. In regard to using a multi-informant approach, due to possible inconsistencies in reports from respondents and due to possible variations in the child's behavior across settings, several different informants should provide information to complete the assessment (e.g., both parents, or a parent and a daycare provider). Using different methods of assessment and obtaining information from several sources will provide the most representative information about the child and lead to informed diagnostic decisions. Since children with ASD commonly exhibit comorbid disorders and challenging behaviors, it is also recommended that clinicians assess these areas. Measures such as the BISCUIT are suggested because these related areas are part of the assessment tool; however, there are other specific measures that can also be used for measuring challenging behaviors and psychopathology in children with ASD, though it is outside the scope of the current chapter. By following the recommendations above, the clinician should be able to obtain a comprehensive clinical picture and determine if an ASD diagnosis is appropriate for the child.

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6

Psychological Theories of Childhood Autism

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Keywords

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The many theories of autistic behavior in young children may be classified into two large categories: those that approach the disorder from the biomedical perspective and those that approach it from the psychological perspective. The biomedical theories attribute the disorder to heritable or genetic factors, neurological malfunction or impairment, structural brain abnormalities, neurochemical influences, or neurodevelopmental pathological processes. The psychological theories attribute the disorder to parenting behaviors, inherent socio-emotional limitations, cognitive deficits, or atypical conditioning and learning in the early years of development. This chapter reviews some of the major psychological theories and discusses their key components.

Our aim is to survey the major psychological theories of childhood autism. We provide critical comments along the way and elaborate at times on key aspects of the most promising theories, namely, those that conceptualize the disorder from the behavior analytic point of view. We end the chapter with a call for additional theoretical work that links the development and elaboration of autistic behavior in young children to the concepts and principles embodied in the theory and philosophy of behavior analysis.

Defective Parenting Theory

A small number of outdated theories blame autism on poor parenting by claiming that autism results from parents' inability to properly relate to their child. Representatives of this view are the psychogenic theory of Bettelheim (1967), which has its roots in orthodox psychoanalytic theory, and the bonding theory of Tinbergen and Tinbergen (1972, (1983) and Welch (1988).

Psychogenic Theory

The psychogenic theory of Bettelheim (1967) maintains that autism in young children is an emotional disorder resulting from the behavior of cold and unresponsive parents who harbor hostile impulses toward their child. As a result, the child develops autism as a defense against such parental behavior. Treatment involves separating the parents from their child, generally by placing the child in a warm and loving residential program in which he or she is given as much freedom as

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possible. Any indication that the child is receding into autism is countered with unconditional love and affection. Parents are allowed to participate in the treatment to help resolve the unconscious conflicts that are said to be typical of themselves as well as their child.

Bonding Theory

Developed by Niko Tinbergen, a 1973 Nobel Laureate in the field of ethology, and his wife, a long-time teacher of children with autism, this theory holds that autism is a result of inadequate bonding between the mother and her child (Tinbergen and Tinbergen 1972, 1983). Adherents to this view, which includes Welch (1988), a psychiatrist, also believe that the child with autism is overly fearful and frustrated because of the parents' awkward and unsuccessful attempts at socialization, and that these defensive, emotional reactions over-generalize to social stimuli such as faces and facial expressions. They maintain that the child is too young and insecure to conquer his or her fears and frustrations due to the failure to adequately bond with the mother, thereby creating feelings of inadequacy and an accompanying sense of loss and loneliness. According to this theory, these problems can be resolved by the mother holding her child, even forcibly and for long periods of time, while repeatedly expressing words of love, devotion, and affection. This practice, they explain, aims to break down the child's autistic symptoms.

Comments

Nearly 50 years ago, Rimland (1964) reviewed the evidence and arguments for Bettelheim's psychogenic theory and concluded that it was an "inadequate and pernicious hypothesis." Since then, adherents to the theory have all but disappeared, at least in the USA. Thankfully, no credible scientists blame autism on bad parenting any more. And, while bonding theory and "holding therapy" gained some popularity in the 1980s, they are also perspectives with few, if any, supporters today (Schreibman 2005). While they rightfully belong to a bygone era, we will see later on that these misguided theories persist as animus to discussions on the role parents play in the development of their child's behavior, including autistic behavior.

Cognitive Deficit Theories

We summarize and briefly critique three cognitive deficit theories of autism. These are the impaired meta-representational theory (Frith 1989; Leslie 1987; Baron-Cohen and Cohen 1991), the impaired knowledge acquisition process theory (Sternberg 1987), and the impaired Piagetian mental structures theory (Morgan 1986).

Impaired Meta-Representation

Along with Kanner's original observation and report of children with autism was his speculation that the course of the disorder was constitutional in nature (Kanner 1943). Later, Kanner (1949) emphasized that the constitutional deficits were chiefly in the social and emotional domains.

An extended version of Kanner's position is given by Hobson (1989). Summarizing Hobson's position, Matson (1994) wrote that, "… autism stems from constitutional limits on emotional reactivity that alter the necessary sharing of subjective interpersonal experiences. Such limits impede abstraction, symbolic representation of thought/feelings, and emphatic recognition of feeling and thought in other persons. Social and affective development is undermined, leading to secondary, lower-order deficits in cognitive and language functions" (p. 40). Although the Kanner–Hobson hypothesis—the ability to represent the thoughts and feelings of oneself and others is deficient in children with autism—is not well known per se, it is nonetheless the key element in the impaired meta-representation theory.

Popularly known as the "theory of mind" or "ToM" deficit, the impaired meta-representational viewpoint holds that normal social interaction, communication, imagining, pretending, and so forth have their origins in the growing capacity to represent the mental states of oneself and others (Wing 1989). A disturbance in the development of this capacity, according to Frith (1994), affects "the thinking of autistic people, making them unable to evaluate their own thoughts or to perceive clearly what is going on in someone else's mind" (p. 117). For Malle (2002), the inability undermines the development of "all conscious and unconscious cognition" and leads to what Baron-Cohen (2001) calls "mind blindness."

The impaired meta-representation theory is currently the most vigorous cognitive deficit theory of autism. Among the most active contributors are the British psychologists Frith, Baron-Cohen, Leslie, and Wing, who set for themselves the task of searching "… for a single cognitive component that would explain the deficits, yet still allow for the abilities that autistic people display in certain aspects of interpersonal actions" (Frith 1993, p. 110–111). They take the position that while autism is an organic disease that cannot be cured, much can be done to make life more hospitable for those who are afflicted.

Impaired Knowledge Acquisition

According to Sternberg (1987), autism may be understood in terms of his "triarchic" theory of intelligence. The relevant subset of this theory pertains to the relationship between intelligence and the mental life of the child. For the child with autism, the knowledge acquisition process, which involves selective encoding (discrimination), selective combination (construction), and selective comparison (integration), is applied in a manner that is "misselective" with respect to the social environment. As Sternberg explains it, the child selects aspects of social stimuli in certain areas, especially the linguistic-symbolic area, in a manner that eventually produces symptoms of schizoid personality disorder, which includes impaired social behavior and interpersonal interaction as well as emotional deficits and cognitive limitations.

Impaired Mental Structures

In a speculative effort to show how Piagetian theory might be applied to children with autism, Morgan (1986) suggests the child may have a permanent or at least a long-standing imbalance between accommodation, which includes the figurative function of presenting symbolic meaning, and assimilation, which includes the operational function of conceptualizing symbolic meaning (see Cowan 1978). Morgan further speculates that the child's repetitive and restrictive motor behavior and lack of imaginative and symbolic play may be related to an arrest of certain operative functions at the sensorimotor level.

Morgan (1986) also believes that young children with autism may have an abnormal concept of object constancy. In his view, parents and other people are the least predictable "objects" in the environment. The child with autism resists people on this basis—unpredictability—and is instead drawn to, and forms attachments with, actual objects in the physical environment with predictable features, for instance, a toy car or a stuffed animal. Morgan asserts that an abnormality of this sort in object constancy undermines the formation of normal social attachments and interferes with the development of advanced cognitive activities, such as symbolic play, which he claims are necessary for the early development and elaboration of verbal and social behavior.

Comments

These three theories of childhood autism uniformly regard the observable behavior of a child as indicative of a deficiency or abnormality in a hypothetical mental process, an undetected neurological condition, or more likely, a combination of these constructs. In other words, the theories rest on unobserved and unverified events in both the mental and the neurological domains.

Consider the dominant cognitive deficit theory, the impaired meta-representation theory. Said to be localized in one of the least understood regions of the human brain, the orbitofrontal cortex (Baron-Cohen et al. 1994), ToM and the meta-representational processes it entails is said to enable a child "… to infer the full range of mental states (beliefs, desires, intentions, imagination, emotions, etc.) *that cause action*" (Baron-Cohn 2001, p. 174, italics added). This causal agent is revealed, and its workings evaluated, by a "false belief task" (Caruthers and Smith 1996) that is given to assess a child's ability to predict the actions of another person on the basis of an "inferred mental state that differs from reality" (Bloom and German 2000). For some researchers, failing a false belief task is tantamount to a diagnosis of autism, and the child with autism, in turn, is described as having a deficiency in meta-representation, a defective ToM, a damaged orbitofrontal cortex, or a combination of these disturbances.

A less gratuitous interpretation of the false belief task is offered by Schlinger (2009), who writes that, "a certain level of verbal fluency is necessary to make an inference about what another person might be thinking, in addition to predicting what he or she might do" (p. 442). Studies have repeatedly confirmed this by showing a high, positive correlation between performance on a false belief task and the level of vocabulary development of the children tested for ToM (e.g., Astington and Jenkins 1999; Bretherton and Beeghly 1982; Happe 1995; Shatz et al. 1983). In one such study, by Happe, it was noted that, "Unlike normally developing 3- and 4-year-olds or nonautistically mentally handicapped individuals, subjects with autism in this sample needed to have a high level of verbal ability on the British Picture Vocabulary Scale (BPVS) in order to stand a chance of passing false belief tests. In addition, a very high level of verbal ability was found among those autistic subjects who passed the theory of mind tasks" (p. 853). Studies with deaf children and children with autism report similar rates of failure on the task (Peterson and Siegel 1999), and other studies comparing children with autism to children of typical development and children with intellectual disabilities show that failing the task is not limited to children with autism but instead is related to the sophistication of the child's verbal behavior (Yirmiya and Schulman 1996). While "reading minds" and engaging in related "perspective-taking" behaviors are undoubtedly important to the acquisition of verbal and social behavior, and vice versa, it is difficult to see the value of casting the process by which this occurs in the light of meta-representational theory. Furthermore, the autism spectrum contains a very diverse array of deficits, which vary greatly from person to person, so to ascribe the cause of all of these deficits to a lack of perspective-taking ability (a specific skill repertoire) seems a bit overly ambitious.

The problem with the cognitive deficit theories is easy to spot. The basis for meta-representation theory, for example, is the accuracy of child's verbal-vocal report of where another person will look for a hidden item that was moved without their knowledge on a false belief task. Transforming this direct observation of behavior into unobservable processes and hypothetical mechanisms is congenial to mentalism. As Moore (2003) describes it, theorizing with mentalism is a three-stage process involving (1) collecting observations of behavior (e.g., performance on a false belief task), (2) hypothesizing the process that appears to underlie the behavior (e.g., meta-representation), and then, after additional observations of behavior (e.g., more performances on false belief tasks), (3) constructing a formal theoretical account of the mechanism responsible for the behavior (e.g., ToM), including its neurological basis (e.g., the orbitofrontal cortex).

The theorizing process described above is common in cognitive psychology and Skinner criticized it throughout his long career as circular, mentalistic, reductionistic, and impractical (e.g., Skinner 1978, 1987; see also Reese 1996). To elaborate on these familiar criticisms would take us far afield (for a cogent summary, see Moore 2003). We will, however, develop a case against reductionism in the context of the behavior analysis theories of autism that give causal status to biological factors.

Both Sternberg's (1987) and Morgan's views are compatible with the impaired meta-representation theory and therefore are subject to the same criticisms. In addition, Sternberg takes the position that cognitive defects are antecedent to deviant social behavior. If one were to take a different position, such as that taken by Skinner (1957), that there is an overlapping relationship between cognitive, social, and verbal behaviors, then one would expect that deviant social behavior would be antecedent to impaired verbal and cognitive behavior.

Behavior Analysis Theories

The behavioral hypothesis by Ferster (1961), the behavioral theory by Lovaas and Smith (1989), the contingency-shaped disorder in verbal behavior hypothesis by Drash and Tudor (2004), the social communication theory by Koegel et al. (1994), the behavior interference theory by Bijou and Ghezzi (1999), and the stimulus control hypothesis by Spradlin and Brady (1999) constitute the major behavior analytic theories of behavior displayed by children with autism. We will summarize each one, adding details where necessary to clarify or elaborate on key points. Each behavior analytic theory differs from the others, but it is important to note that none of them deny the existence of a biological variable in autism. Rather, they each point to unique behavior–environment relations that can be potential targets for treatment.

The Behavioral Hypothesis

The behavioral hypothesis by Ferster (1961) holds that an experimental analysis of the basic variables determining a child's behavior will show how these variables operate to produce the particular kinds of deficits seen in a young child with autism. Such an analysis, Ferster claimed, would reveal not only the effects of the child's autistic behavior on members of the family, and vice versa, but also how these behaviors and interactions maintain the deficits. He claimed further that the behavior of the parent can forestall or weaken the development of their child's behavior through the reduction of reinforcement, extinction, noncontingent reinforcement, and, to a lesser extent, aversive control. This state of affairs could come about through the disruption of the parents' repertoire (e.g., depression), the prepotency of other behavior (e.g., a strong desire to be active in community affairs), or escape from the child who has acquired aversive properties due to continual screaming, tantruming, and the like. Ferster concluded that, "All of the variables that might weaken the behavior of a child are directly or potentially observable. The data required are the actual parental and child performances and the specific effects on each other, rather than global statements such as dependencies, hostility, or socialization" (p. 455).

A variation on Ferster's (1961) hypothesis, by Drash and Tudor (2004), holds that autism is a contingency-shaped disorder of verbal behavior. On this account, disordered verbal behavior is the result of the contingencies of reinforcement that prevail during the early years of a child's life. Many of these contingencies shape and sustain escape and avoidance behaviors that reduce a child's contact with the verbal community. Compared to these contingencies of negative reinforcement, the contingencies of positive reinforcement are far less prevalent, leading to additional complications in maintaining contact with the verbal community and developing an appropriate verbal repertoire as a result of that contact. As Drash and Tudor explain, the verbal community and the contingencies of reinforcement rest with the family and in the hands of parents as a matter of their everyday child-rearing practices.

Drash and Tudor (2004) make the frank observation that a parent of a child with autism may reinforce behaviors that are consistent with a diagnosis of autism. As alarming as that may seem, it must be remembered that all parents occasionally reinforce their child's inappropriate and undesirable behaviors, and that parents of a child with autism are no exception to this universal truth. By the same token, parents reinforce their child's desirable and appropriate behaviors, and parents of a child with autism are not exempt from this universal truth, either. Further, as Drash and Tudor point out, a parent of a child with autism—or any parent of any child, for that matter—can benefit from learning how to differentially reinforce their child's verbal-vocal behavior in conjunction with extinguishing troublesome behaviors such as hitting, kicking, and tantruming. In the language of behavior analysis, this is called contingency management.

Managing (and mismanaging) the contingencies of reinforcement in the home is sometimes misconstrued to mean that autism is caused by parents who are either unfit or unwilling to raise their child. A behavior analytic version of Bettelheim's (1967) defective parents theory, in other words, is implied. Yet, it is obvious that the contingencies of reinforcement in the home have absolutely nothing to do with Bettelheim's misguided theory. Instead, the theory and practice of managing contingencies capitalizes on the undisputed fact that parents play a decisive role in their child's development, and that a good deal of parenting in the early years is straightforward contingency management (e.g., Hart and Risley 1995).

Little else need be said again about the defective parenting theory and its superficial relation to Ferster (1961) and Drash and Tudor (2004) except to recall what Rimland (1964) wrote many years ago about the defective parenting theory as an "inadequate and pernicious" point of view. To that we might add the ironic twist that practitioners today regard parents as the solution to their child's problems, not the cause of them (e.g., Latham 1990).

Lovaas and Smith

Lovaas and Smith (1989) present their behavioral theory in terms of four tenets: (1) The behavior of children with autism can be accounted for by the laws of learning. (2) Children with autism show many specific deficits rather than a general or central deficit that if corrected would lead to large-scale improvements in behavior. (3) Once a special learning environment is created, children with autism can be taught age-appropriate skills and abilities. (4) The failure of the normal environment and success in the special environment indicates that children with autism represent a mismatch between the normal environment and their nervous system.

The first two tenets—that the laws of learning can account for autistic behavior and that children with autism show many specific deficits rather than a central deficit—are in accord with Ferster's (1961) and Drash and Tudor's (2004) respective hypotheses as well as with the volumes of studies to which these two tenets apply. The third tenet—that children with autism can learn like other children when placed in a special environment—is also compatible with Ferster's and Drash and Tudor's perspectives. As a matter of fact, the rising tide of evidence on the effects of early intensive behavior intervention since Lovaas published his landmark study in 1987 elevates this tenet to an axiom (e.g., Odom et al. 2003; Virues-Ortega 2010).

The fourth tenet—that the failure of children with autism in the normal environment and the success in special environments may be due to a mismatch between their nervous systems and the normal environment—is *not* in accord with Ferster (1961) or Drash and Tudor (2004). Perhaps, Lovaas and Smith took this perspective to refute the idea that autism is a disease or illness, as many psychiatrists, pediatricians, and cognitive psychologists tend to believe, or that it is a result of defective parents, as Bettelheim (1967) claimed long ago. In any case, we will argue later on that the postulation of a mismatch between the normal environment and the child's nervous system is inconsistent with behavior theory and philosophy.

Social Communication Impairment

The social communication impairment theory by Koegel et al. (1994) holds that a defective neurological process can result in inappropriate socialization, in turn leading to the development of undesirable behaviors (e.g., stereotypy, tantruming), poor social skills, and deficient verbal behavior. The many and varied behaviors of the child with autism, in other words, may be traced to impaired socialization, which is itself caused by a neurobiological deficit of unspecified origin. Postulating an organic deficit—like the mismatched nervous system of Lovaas and Smith

(1989)—is inconsistent with behavior theory and philosophy.

An emphasis on the interrelatedness of behavior and the primacy of social behavior is well taken in the light of research showing that improvements in social skills may lead to concomitant reductions in disruptive behaviors such as yelling, screaming, and shouting (Carr and Durand 1985; Koegel et al. 1992). Further, the theory is compatible with Drash and Tudor (2004) in placing deficient verbal behavior and its undesirable effects on social behavior at the center of the disorder.

Behavior Interference

The behavior interference theory by Bijou and Ghezzi (1999) seeks to account for the behavior of young children with autism in the early stages of development. The theory has four tenets: (1) Children with autism are inclined to escape and avoid mild tactile and auditory stimuli. (2) This inclination interferes with the process by which social discriminative and conditioned reinforcing stimulus functions typically arise. (3) Interference in this process contributes to the acquisition and maintenance of deficient emotional, social, and communicative behavior. (4) Repetitive and restricted behavior is an automatically reinforced class of operant behavior that, first, is on a continuum with the exploratory behavior observed in typically developing children, and second, becomes a preferred alternative to social sources of reinforcement.

The first tenet of the theory—that children with autism are inclined to escape or avoid tactile and auditory stimuli—requires some elaboration (see Hayes 1999). The early weeks and months of a child's life are characterized by frequent and short periods of highly variable tactile and auditory stimulation provided by parents as part of their normal child care routine. These periods alternate with periods of less varied stimulation when the child is alone, and with periods when there is little or no auditory or tactile stimulation when the child is asleep. As the child matures, sleeping decreases in frequency and duration, which is to say that the child is more often awake and for longer periods of time. The frequency and duration of highly variable tactile and auditory stimulation provided by parents ordinarily increases to match the child's waking period.

If this increase in the frequency, duration, or variability of tactile and auditory stimulation by the parents goes beyond the child's preferred or "baseline" level of stimulation, then access to less frequent, less varied, or shorter periods of auditory and tactile stimulation should function as an operant reinforcer (Timberlake and Allison 1974). What the child is capable of doing by way of effectively reducing this increased level of stimulation is limited to responses such as fussing, crying, squirming, tensing, or turning away from the parent(s). A contingency of negative reinforcement is thus established whereby the parents' response to their child's unruly behavior is naturally to reduce contact, the effect of which is (1) to reinforce the child's fussing, crying, etc., and (2) to reinforce the parent's behavior by the calming effect that this reduced contact has upon their child as well as upon themselves and family members. What occurs under these conditions is atypical development of social discriminative and conditioned reinforcing stimulus functions, which in turn leads to deficient emotional, social, and communicative behavior and a concomitant rise in automatically reinforced repetitive and restricted vocal and motor responses.

The second tenet of the theory—that the development of ordinary social discriminative and conditioned reinforcers and their attendant motivational operations is obstructed in the early life of the child—also deserves some elaboration. In the context of ordinary child rearing activities, conditioned social reinforcers and the discriminative stimuli and motivational events to which they relate are believed to develop in the following way (Bijou 1993; Bijou and Baer 1965). As mothers of typically developing children engage in routine child care activities, for example, feeding, bathing, dressing, and the like, they naturally touch, hold, and vocalize to their child. The stimuli that the mother generates—her presence, proximity, odor, movements, holding, talking, touching—acquire conditioned reinforcing and discriminative stimulus functions for her child by virtue of their frequent and consistent relation to the unconditioned positive and negative reinforcement processes inherent in these everyday activities. Given a child with a tendency to escape and avoid cutaneous and auditory stimulation, the stage is set for these positive relations to occur infrequently or inconsistently. Indeed, the mother's mere presence would soon acquire aversive functions by virtue of her frequent and consistent association with stimuli unpleasant to the child. Instead of anticipating the mother's presence by raising his or her arms, for instance, the child would look away and perhaps try to move away as well.

A closely related example is seen when a mother plays with her typically developing child by cuddling, rocking, talking, singing, and so on. The tactile and cutaneous stimuli she provides to her child are commonly associated with mutual joy, affection, and love. But for children with autism, the stimuli arising from mother's playful activities may be associated with pulling away, covering the ears, and gaze aversion (Mirenda et al. 1983). Under these circumstances, there is little chance that the mother's playful behaviors would acquire positively reinforced functions. Further, if the child's resistance or unresponsiveness to the mother's playful behaviors results in her reducing or terminating her playful overtures, then the child's resistive or unresponsive behaviors would be negatively reinforced by the contingent removal of these unpleasant, aversive stimuli.

Lovass (1966) offered a similar analysis of the abnormal development of social discriminative and conditioned reinforcing stimulus functions: "Normal development presupposes the acquisition of a large variety of secondary reinforcers. It follows that the child who has failed to acquire such reinforcers should demonstrate a deficiency in the behaviors which would have been reinforced. In the extreme case of complete failure to acquire secondary reinforcers, the child should evidence little, if any, social behaviors. That is, the child should fail to attend to people, to smile, to seek company, to talk, etc. because his environment has not provided him with the rewarding consequences for such behavior, or because he is unable to appreciate that consequences are rewarding. It is apparent that such failure in the acquisition of secondary reinforcers need not be complete, but may be partial" (p. 118–119).

Stimulus Control

According to Spradlin and Brady (1999), the deficits in verbal and social behavior seen in children with autism can be traced to limitations in the development of stimulus control in the early years of life. Reminiscent of Morgan's (1986) claim regarding problems with object constancy, Spradlin and Brady argue that compared to the physical environment, the relations between and among events in the social environment are notoriously inchoate and inconsistent. This discordance makes it difficult for any child to properly discriminate the prevailing contingencies of reinforcement in the social environment. For children with limitations, for instance, in relating one antecedent stimulus to another, as in conditional discrimination learning, for instance, the difficulty is even greater, and for some, insurmountable.

Spradlin and Brady (1999) identify a child's early years as critical to establishing socially appropriate stimulus control. How conditioned stimuli for feeding behavior, for instance, arise from the mother as she nurses her baby is used to illustrate the impact that impairments in stimulus control could have on the developing infant. In theory, impairments in respondent learning, for example, could relate to impairments in the upstream processes of habituation and sensitization and lead to impairments in the downstream processes of conditional discrimination and stimulus equivalence.

If Spradlin and Brady (1999) are near the mark, the acquisition of social discriminative and conditioned reinforcing stimuli would be abnormal, leading eventually to difficulties in acquiring age-appropriate social, emotional, verbal, and intellectual behaviors. Further, a repertoire of negatively reinforced undesirable and disruptive behavior would most likely predominate, for instance, in response to the parents' repeated attempts at encouraging their child to look at them, to speak, to sit still, to play properly with toys, other children, and so on. The opportunities available to the parents to shape and maintain desirable behavior would probably diminish under these conditions, too. Moreover, with a social repertoire restricted mainly to reinforced escape and avoidance behaviors, the child presumably would have plenty of time and opportunity to interact with nonsocial sources of stimulation, for example, repetitive and restricted motor and vocal behaviors.

What Spradlin and Brady (1999) believe is needed to prevent or remedy these problems is a highly structured environment in which the relations between specific antecedent stimuli, responses, and consequences are presented deliberately, consistently, and frequently. They cite the early work of Lovaas (1977) as a prime example of how a teaching environment can be arranged that achieves this level of structure.

Comments

Spradlin and Brady's (1999) stimulus control theory is entirely compatible with Bijou and Ghezzi's (1999) behavior interference theory; in fact, the two overlap considerably to form a workable theory of childhood autism. Further, the two theories are compatible with Ferster's (1961) behavioral hypothesis and Drash and Tudor's (2004) verbal behavior hypothesis. While Lovaas and Smith's (1989) behavior theory and Koegel et al.'s (1994) social-communicative theory are compatible with the other behavior analytic approaches, they differ from them on the role of biological factors in the behavior development of young children with autism. It is a significant theoretical difference, one that we will elaborate upon below.

While some behavior analysts maintain that the independent variables of behavior are environmental conditions and events, others believe that they consist of both environmental and biological variables (e.g., Pierce and Cheney 2008). Lovaas and Smith (1989) and Koegel et al. (1994) appear to subscribe to the latter position. A major problem with this perspective is that the biological variables to which Lovaas and Smith and Koegel and his colleagues refer are far too ill-defined to serve as workable variables because no specific aspect of the nervous system, the environment, or the interaction between the two is offered as the cause or catalyst for autistic behavior. Said another way, the Lovaas and Smith and the Koegel, Valdez-Manchaca, and Koegel theories would be strengthened by replacing vaguely defined neurological processes with a specific, observable condition in the neurology of the child and a specific, observable condition in the child's environment that interacts with the child's neurology to produce autistic behavior in all of its varied forms and functions.

The allure of this strategy is the promise of integrating biological and behavioral variables to form a comprehensive theory of autistic behavior. How this might be accomplished is unclear, yet it would seem to start with the assumption that behavior analysis is a branch of physiology, and as such, behavioral phenomena can and indeed should be reducible to physiological phenomena (Schaal 2003). However, behavior analysis, like all other sciences, cannot and need not be reduced to any other science. One core stipulation of behavior analysis, articulated by Reese (1996), is that "the concepts in an explanation must be at the same level as the phenomena to be explained and must be in the same domain as this phenomenon" (p. 62). This stipulation is reminiscent of Skinner's (1950) contention that an explanation for a given phenomenon is useless if it "appeals to events taking place somewhere else, at some other level of observation, described in different terms, and measured, if at all, in different dimensions" (p. 193). Violating this stipulation is not necessary fatal, however, provided that violating it affects a second core stipulation, a marked improvement in the ability to predict and control behavior. Is knowledge of a child's physiology useful in predicting and controlling his or her behavior? The resounding success that applied behavior analysis has had, for example, in treating and educating young children with autism clearly shows that knowing about a child's physiology does not improve the ability to know how to predict and control the child's behavior. It is the tradition of behavior analysis to emphasize its applied dimensions, and it is in that tradition that Reese argued that ignoring physiological processes "seems unlikely to be an obstacle to progress in behavior analysis" (p. 68).

The alternative view is that it is entirely possible and far more effective and expedient to work at a purely behavioral level, that is, at the level of the child interacting in and with the physical and social environment. As Schaal (2003) understates it, "there is sufficient order in the relations between behavior and environment studied by behavior analysts to build a science of behavior independent of neurophysiology" (p. 86).

While the biological participants involved in the interaction between behavior and environment are given no causal status in behavior analysis, they may sometimes function as discriminative stimuli, as when a child's teething sets the occasion for a call to the dentist, or as motivational operations, as when a child's first steps establishes walking as a reinforcer. As Reese (1996) points out, "physiology deals with the sources of such products; behavior analysis can and sometimes does deal with the effects of some of these products, and the effects of the products can be understood without understanding the sources of the products" (p. 62). In sum, if there are no logical, empirical, or practical reasons for giving biological factors causal status, then there is no compelling reason to reduce behavior to the actions of a mismatched or deficient nervous system, or for that matter to locate the study of childhood autism in the subject matter of neurology.

If and when behavioral data are to be integrated with biological data in understanding the etiology of autism, they must be combined as equal contributors to a new, multidisciplinary science. For example, future interdisciplinary research may help reveal how neurochemical variables interact with behavior–environment contingencies in unique ways in individuals with autism spectrum disorders. Similarly, future research may reveal how learning under different environmental contingencies leads to lasting structural and chemical changes in the brain. All such research would examine bidirectional relations between behavioral and biological variables, without reducing the data of one science to another.

Conclusions

The value of viewing childhood autism from a behavior analytic perspective, as opposed to a cognitive perspective, is that it deals exclusively with observable and verifiable variables and relationships between the behavior of a child and his or her physical and social environment. Hypothetical variables and mental processes such as the "inability to represent mental states" are excluded precisely because they are unobservable and unverifiable, and because they are not useful in advancing the goals of predicting and controlling behavior. Findings from physiological research are also excluded from behavior analysis, for the most part, not because they refer to unobservable and unverifiable variables, but because they are inconsistent with the stipulation regarding different levels and different domains, and because they are seldom relevant to the goals of predicting and controlling behavior. These considerations put cognitive and physiological psychology both in the position of being unable to add any new or useful information about behavior, including how to help young children with autism lead successful lives.

We say "for the most part" in describing behavior analysis as excluding findings from physiological psychology. The exceptions are Lovaas and Smith (1989) and Koegel et al. (1994). Eliminating their respective allusions to mismatched nervous systems and defective neurological processes would unite these theories with the other theories and hypotheses in behavior analysis to form a theory of autism that is thoroughly consistent with the philosophical precepts and theoretical concepts and principles of behavior science.

Judging by the small amount of work done to date by behavior analysts in developing a theory of childhood autism, it may be some time before a united theory of autism is available. One explanation for this unfortunate delay begins with the observation that behavior analysts have been applying the principles of behavior to treat and teach young children in particular with marked success for more than 30 years. Perhaps, theoretical developments have been slowed by this applied success; after all, as Skinner noted many years ago, "The ultimate criterion for the goodness of a concept [is] whether the scientist who uses the concept can operate successfully upon his material" (1972, p. 383). In this light, it may be hard to see the value of behavior theory and philosophy. We would argue that developments in behavior theory and philosophy brought "successful working" to applied behavior analysis in the beginning, and further developments in theory and philosophy will continue to guide the practice of applied behavior analysis to even greater heights now and in the future.

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Family Adaptation to a Diagnosis of Autism Spectrum Disorder

7

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Family systems · Stress

The diagnosis of an Autism Spectrum Disorder (ASD) in one or more children is a pivotal and sometimes traumatic experience that has a significant impact on the family. Initially, parents may be concerned about the development of language skills, emotional reciprocity or restricted activities and interests of their child before seeking an autism assessment. For parents of children at the higher functioning end of the autism spectrum, concerns may only begin to surface when the child struggles to make friendships at school. Parents participate in numerous assessments and medical investigations before being told about their child's disability. For many, it is months or years after parents raise initial concerns about their child's development that they receive a formal diagnosis of an ASD. The diagnosis can be met with a mixture of emotions, including grief, shock, guilt, resentment and relief that there is finally some recognition of their concerns. This lengthy assessment process, often involving multiple health professionals adds additional stress and burden on the parents. The way in which families adapt to the initial diagnosis as well as their ongoing wellbeing is of critical importance. Understanding family adaptation and coping mechanisms allows health professionals to predict the intervention needs of families and individual family members.

This chapter will review the major models of family adaptation to crises or stressful life events that have been proposed to explain why some families adjust positively to disability within the family while others do not. Further, it will consider the relative impact of an Autism Spectrum Disorder diagnosis on the family compared to other diagnoses such as intellectual disability, Down syndrome and other developmental disorders. It will then review the literature on the impact of an ASD family member (aged 0 to 6 years) on siblings, parents and grandparents. Finally, recommendations for early intervention and support for family members will be made.

Models of Family Adaptation to Stressful Life Events

Psychological adaptation to stressful life events has been a topic of much research interest for decades, with numerous theories proposed to better

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understand adjustment to many life stressors such as families' responses to war, war separation and return of war veterans (Hill 1949; McCubbin and Patterson 1982), army families' relocation overseas (Lavee et al. 1985), death and dying (Kübler-Ross 1969), bereavement (Calderwood 2011), or adaptation to chronic illness and disability (Bishop 2005; Drotar et al. 1984; Glasberg et al. 2006; Jones and Passey 2004; Livneh and Parker 2005; Orsmond and Seltzer 2009; Perry 2004; Seligman and Darling 2007). Various models have been proposed to explain the process of family adaptation to stressful life events, from stage approaches to coping and the cognitive appraisal model, to approaches that stress the role of the entire family system, and those that examine how the stressor event, family coping resources, and the appraisal of the event interact to determine how well the family copes or adapts to change. Such models allow for an insight into how families adapt to a diagnosis of ASD in the family, and allow for an examination of the factors that may assist families to mobilise their coping resources to ensure eventual adaptation to and acceptance of their child's diagnosis to plan for their future.

Stage Models of Family Adaptation in the Disability Arena

Numerous models have been tested and offered in the disability and rehabilitation literature (e.g. Calderwood 2011; Frain et al. 2007; Jones and Passey 2004; Kübler-Ross 1969; Lazarus and Folkman 1984; Livneh and Parker 2005; Livneh and Martz 2007; Morgan 1988; Orsmond and Seltzer 2009; Perry 2004; Weber 2011). Some early work in the field of adaptation focused on stage approaches to coping, suggesting that individuals pass through a series of stages of adjustment (e.g. Kübler-Ross 1969). A number of variations of stage models have been proposed (e.g. Anderegg et al. 1992; Duncan 1977; Fortier and Wanlass 1984; Kübler-Ross 1969; Prochaska and DiClemente 1983; Schontz 1975), with most including the following broad stages: (a) shock and denial; (b) emotional disorganization (e.g. guilt, blame, shame, anger); and (c) emotional organization (such as acceptance or adaptation; Blacher et al. 2007). Many also include a maintenance stage to address what happens after acceptance has been reached (e.g. Prochaska and DiClemente 1983).

One of the most wellknown stage models was proposed by Kübler-Ross (1969) in her work on adaptation to death and dying in terminally ill patients. Based on research and interviews with over 500 patients, she described a five-stage model, where individuals facing their death underwent stages of (a) denial; (b) anger; (c) bargaining; (d) depression and (e) acceptance. She did not insist that all individuals passed through each stage, or that they did so chronologically. Although originally applied to individuals suffering from terminal illness, Kübler-Ross expanded the model to apply to any form of catastrophic loss or significant life event such as the death of a loved one or onset of a chronic disease or illness. As such, her stage model approach is one that has been applied to the disability literature and parallels can be drawn with parents' adaptation to a diagnosis of a child with ASD.

While stage theories can offer some insight into the process of family adaptation to disability, in general, stage models have been criticized for their linearity, and the assumption that individuals must master each stage in sequential order. Bandura (1998) argued that in a genuine stage theory, each stage must be qualitatively different, must occur in a fixed sequence, must apply to all individuals affected, and should not be reversible. Although few take such a purist view, it is widely believed that stage theories of adjustment are limiting and that the negativity embedded within such models tend to view individuals from a deficit perspective (Blacher et al. 2007), rather than allowing for a focus on the resources and supports that the individual has to effect positive change and eventual acceptance.

Cognitive Appraisal Model of Stress and Coping

Another model that has been highly influential in shaping the adaptation research is the cognitive appraisal model of stress and coping developed by Lazarus and Folkman (1984), although the focus has still remained largely on the individual. Lazarus and Folkman (1984) defined coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). The cognitive appraisal theory suggests that when an individual is met with a situation or experience where they become aware of an actual or threatened change (e.g. having a child diagnosed with an ASD), they undergo an initial evaluation of its potential significance (primary appraisal). In their appraisal of the situation, the individual makes a judgment about whether the encounter is irrelevant (carries no implication for the person's wellbeing), benign-positive (enhances the person's wellbeing or promises to do so), or stressful (where some form of harm or loss has happened or is anticipated, or a challenge is expected (Lazarus and Folkman 1984). Secondary appraisal is a judgment about what might and can be done. It involves an evaluation of the options for coping, whether one can apply a particular strategy effectively, and whether a given coping option will accomplish what it is supposed to. The individual's belief that the strategy will achieve the desired outcome (outcome efficacy) and that he or she can effectively exercise that strategy (self-efficacy) are important determinants of coping (Moos and Holahan 2007). A third type of appraisal, reappraisal, occurs when the individual changes his or her original appraisal of a situation on the basis of new information from the environment.

Like Kübler-Ross ' (1969) stage model, the appraisal process is thought to be relevant to how parents cope with a diagnosis of a disability (Trute et al. 2010). However, although both theories offer a way of understanding individual adjustment, they are less useful in explaining the role and the influences of the family in the coping process. Furthermore, many of the theoretical models that have been applied to family adjustment to stressful life events have been based on a pathological model of adaptation, with the research focus being on maternal reactions to the birth of a child with a disability. Many efforts to apply theoretical models to better understand coping and adaptation to a diagnosis of a disability have moved away from a focus on individual pathology or the mother-child dyad, towards models that incorporate the role of the entire family system.

Family Systems Theory

The 1970s saw the development of family systems theory, which rejects the view that individual linear relationships characterize family life and that the only relationship of importance is the mother-child dyad (Seligman and Darling 2007). The theory proposes that individuals cannot be understood in isolation, and that it is essential to view them as part of their family unit. It sees families as systems of interconnected and interdependent individuals, and includes four subsystems: (a) marital; (b) parental; (c) sibling; and (d) extended family (Meadan et al. 2010). When a child is diagnosed with ASD, the adjustment of all family members must be taken into account, and the unique needs of each of the subsystems recognized. Family systems theory has had wide application in the stress and coping literature, and there is growing consensus that when an individual experiences difficulties or crises, a systems approach is essential to understanding the impact on the family. While the earlier conceptualisations of family systems theory were still focused on dysfunction, research is now moving towards examining stress, coping, support networks and effects on siblings and other family members to investigate successful, resourceful ways that families adapt (Jacques 2006).

ABCX Family Crisis Model

Perhaps the most well-known model used to understand family stress and coping is derived from Rueben Hill's classic ABCX family crisis model (Weber 2011). Hill (1949) studied families in wartime, and examined family adjustment to separation and reunion of soldiers during this

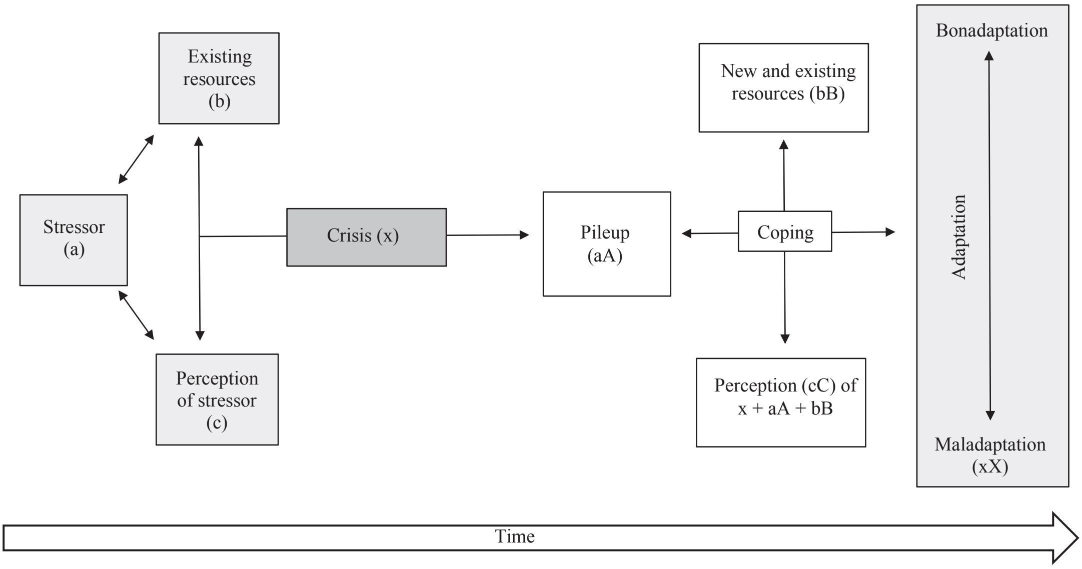

Fig 7.1 The Double ABCX Model

period. He developed his theory of family crisis to explain how families respond to stressors, and how some were able to adapt in a positive way, while others cope poorly after a stressful event. Hill's ABCX formula has become the basis of most family stress models, and its variables remain a foundation of current family stress theory (Weber 2011). Hill's original conceptualization focused on precrisis variables in families, and examined how the stressor event (Factor A), the family's crisis-meeting resources (Factor B), and the definition or appraisal that the family makes of the event (Factor C) interacted to produce the family crisis (Factor X; Weber 2011). Hill's original model has been extended numerous times, particularly by McCubbin et al. (e.g. McCubbin and Patterson 1982, 1983; McCubbin and McCubbin 1987, 1991), and has undergone significant reformulations with perhaps the most notable being the Double ABCX model (McCubbin and Patterson 1982), the Family Adjustment and Adaptation Response (FAAR) model (McCubbin and Patterson 1983), the Typology or T-Double ABCX model (McCubbin and McCubbin 1987), and the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin and McCubbin 1991).

The Double ABCX Model

McCubbin and Patterson (1983) extended Hill's ABCX conceptualization to develop the Double ABCX model (see Fig. 7.1), which included post-crisis variables to explain and predict how families are able to adapt from crises, and how some do so much better than others (Walsh 1996; Weber 2011). The Double ABCX model extends Hill's by exploring family process not only before but also after the crisis. In this model, the family experiences not only the original stressor (changed from uppercase A in Hill's model to lowercase (a), but also an accumulation (or 'pile-up') of other stressors as a result of the crisis (aA). The family then must use their existing (b) and new (B) resources (including psychological/individual and social/community resources as well as the family resources originally considered by Hill; bB) to develop a broadened perception of the situation which includes the perception of the original event that led to the crisis (c), and the family's perception of the crisis, the pile-up of stressors, and existing and new resources (cC) to determine their level of adaptation (from the positive bonadaption to maladaptation) to the crisis (Weber 2011).

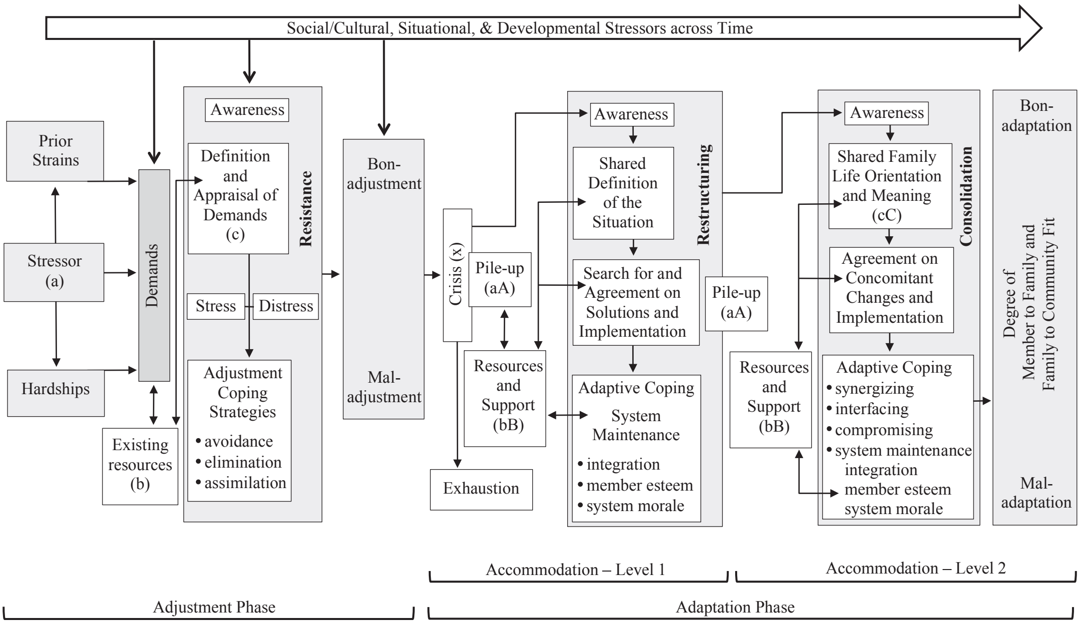

Fig 7.2 The Family Adjustment and Adaptation Response (FAAR) Model

The Double ABCX Model's major contributions to stress theory are the labelling of the interaction of factors A, B, and C as 'coping', and the introduction of the concept 'adaptation' to describe the family's adjustment over time. Here, adaptation refers to changes in the family system that have an impact on family roles, rules, patterns of interaction and perceptions in response to a crisis. It recognizes functioning at two levels, the member-to-family and family-to-community levels (Weber 2011). A further contribution is the recognition that a pile-up of additional stressors on top of the initial stressor could occur. For example, diagnosis of ASD in a family member could contribute to marital strain, pressure to find appropriate schooling, financial pressure due to cost of intervention or inability to both work and care for a child with ASD (McCubbin and Patterson 1983).

Further adaptations to the Double ABCX model: The FAAR model Further adaptations to the Double ABCX model have been offered. McCubbin and Patterson (1983) expanded earlier work to arrive at the Family Adjustment and Adaptation Response (FAAR) model. Based on longitudinal observations of families under stress due to the husband/father of the household being held captive or unaccounted for in the Vietnam War, this expansion attempted to illustrate the process by which families reach precrisis adjustment and post-crisis adaptation (Weber 2011). The model is divided into two phases separated by a crisis: the adjustment phase (ranging from bonadjustment to maladjustment) and the adaptation phase (ranging from bonadaptation to maladaptation). The adjustment phase is a relatively stable period when the family meets demands with little disruption and change to the system. The adjustment phase in the FAAR model incorporates demands, resources and resistance (see Fig. 7.2). Demands can include such things as prior strains or unresolved stressors as well as the stressor itself (a). In the original model, hardship was included, but Patterson (1988) removed this. He later added daily hassles to the list of demands (Patterson 2002). The family's existing resources (b) appear in the adjustment phase of the model. Finally, the model includes resistance to change, which illustrates the family's awareness of the demands of the prior strains, the stressor, the hardships and daily hassles. They then begin to define and appraise the demands (c, analogous to C in the original ABCX formula), and their definition leads to a positive or negative stress state to which they apply adjustment coping strategies. The level of adjustment varies on a continuum from positive (bonadjustment) to negative (maladjustment). When the outcome of the adjustment phase is maladjustment, the family enters a state of crisis. Crises occur when there is an imbalance between demands and capabilities, that is, when the family does not have sufficient resources and coping strategies to meet the demands of the stressor (McCubbin and Patterson 1983).

The second more complex phase of the FAAR model is the adaptation phase, which consists of two levels—Accommodation Level 1 and Accommodation Level 2 (see Fig. 7.2). At Level 1, one or more family members assess the pileup of factors against the resources and support available, and if the resources do not meet the demands, they enter the restructuring phase. Once the family members reach awareness that the existing resources do not adequately meet demands of the pileup, they attempt to come up with a shared definition of the situation. The family then searches for an agreement on solutions and how to implement them, which involves structural changes within the family (e.g. changes in metarules, interaction and behaviour patterns). While these changes are taking place, the family attempts to maintain positive family functioning as they move towards consolidation and into Accommodation Level 2 (Weber 2011). At this second level, there is a shared awareness that the family has made a second-order change that conflicts with prior structure and patterns. The family has generally undergone some changes from Accommodation Level 1 and they continue to make additional changes to support and complement the new behaviour patterns. Consolidation occurs where the family shares an awareness of the changes needed to support a shared meaning of the situation and moves towards a level of adaptive coping. Again, the outcome (depending on the degree of balance of demands and capabilities) is family adaptation on a continuum from positive (bonadaptation) to negative (maladaptation). Those families who are unable to successfully resolve the crisis (either immediately after the crisis presents itself or after failed attempts to progress through the restructuring and consolidation phases) reach exhaustion.

Further adaptations to the Double ABCX model: The typology model of family adjustment and adaptation At the same time as the FAAR model was being further developed and refined, McCubbin and McCubbin (1987) turned their attention to a further extension of the Double ABCX model. They offered the Typology Double (or T-Double) ABCX Model, later called the Typology Model of Family Adjustment and Adaptation, which underscored the importance of family patterns of functioning for adjustment and adaptation (LoBiondo-Wood 2008). This model combined the components of the Double ABCX model (McCubbin and Patterson 1982) with the phases of adjustment and adaptation of the FAAR model (McCubbin and Patterson 1983) and extended previous work by adding a number of family variables to the model. This model introduced family vulnerability (denoted Factor V) to the model, which is determined in part by the concurrent pile-up of demands (stressors, strains and transitions) and the family system's life cycle stage. Another contribution is the addition of Factor T (family type or typology), which included family types of regenerative, resilient, rhythmic and traditionalistic, each with dual dimensions along a continuum. For a more detailed study of these see Weber (2011). The model also included a Problem Solving and Coping (PSC) factor in the adjustment phase that measured the family's management of the stressful situation, and Factor R to represent family regenerativity in the family adaptation phase.

Further adaptations to the Double ABCX model: The resiliency model of family stress, adjustment and adaptation. McCubbin and McCubbin (1991) further expanded on the Double ABCX Model by developing the Resiliency Model of Family Stress, Adjustment and Adaptation, which includes considerations of cultural difference, family paradigms, schemas and coherence (Weber 2011). According to its authors, it emphasizes the post-crisis adaptation phase, and attempts to further explain why some families are more resilient and fare better in recovering from crises than others. The first version (McCubbin and McCubbin 1991) differed very little from the Typology model (McCubbin and McCubbin 1987), although later versions of the Resiliency Model saw more distinct changes, such as the addition of newly instituted patterns of functioning (Weber 2011). It retained Factors V, T and PSC from the Typology model, and added several new interacting components to the adaptation phase, by adding patterns of functioning after the crisis to indicate whether family patterns of functioning were retained, restored or if they were indeed newly instituted. Again, a more detailed description can be found in Weber (2011). In summary, models based on Hill's classic ABCX formula predominate the disability and rehabilitation literature as a framework for understanding the adjustment process of family members to a diagnosis of developmental disability in their child.

Impact on Families: ASD Compared to Families with Children with Mental Retardation, Down syndrome or Other Developmental Disorders

It is well documented that families of children with disabilities experience more stress than those without (Eisenhower et al. 2005; Fisman et al. 1989; Perry 2004; Quintero and McIntyre 2010). Much research has been conducted into the impact of chronic illness and disability on the entire family system. Family adaptation has been studied in reference to general developmental disability (Hastings 2007; Jones and Passey 2004; Perry et al. 2004), ASD (ASD; Dunn et al. 2001; Hastings 2007; Kaminsky and Dewey 2001; Perry et al. 2004; Rodrigue et al. 1990; Rutgers et al. 2007), Down syndrome (Hastings 2007; Kaminsky and Dewey 2001; Perry et al. 2004; Rodrigue et al. 2007; Rutgers et al. 2007), mental retardation (Hastings 2007; Rutgers et al. 2007), cerebral palsy (Lin 2000), cystic fibrosis (Bouma and Schweitzer 1990), blindness (Ulster and Antle 2005), heart-related trauma (Greeff and Wentworth 2009), childhood cancer (Houtzager et al. 2004) and brain injury (Spina et al. 2005). There is little doubt that there are similarities in a family's adaptation to each of these diagnoses, many of which can be better understood through the various models described above. There are, however, some adaptive processes that reflect the unique characteristics of a diagnosis of ASD, and make adaptation of this special population distinct to that of other disabilities.

Adaptation to ASD as Distinct from other Developmental Disabilities: Diagnostic Ambiguity

While there may be many similarities in the adaptation of family members to various chronic illnesses and disabilities, the distinct social deficits and difficulties associated with ASD suggest that the adaptation pathway and experience for this subset of families is unique. Having a family member with any illness or disability can be a challenge for the entire family system, but the unique combination of impairments in autism can place the family at an especially high risk for psychological difficulties (Dunn et al. 2001; Glasberg 2000; Morgan 1988). Compared to other developmental disabilities where a clear genetic cause can be detected (such as Down syndrome or Fragile X syndrome), ASD is an ambiguous and complex condition with an aetiology that is not yet fully understood. Families may find it more difficult to come to terms with a diagnosis given the polygenetic nature of the disorder and the uncertain risk they carry for expression or transmission (Bailey 2007). Additionally, the variability of cognitive ability across the full spectrum of ASDs contributes to parental and sibling confusion regarding diagnosis and prognosis. Research has shown that ambiguous disabilities are associated with poorer sibling outcomes than the presence of a sibling with a more concrete developmental disorder (Macks and Reeve 2007). Diagnostic ambiguity such as that inherent in a diagnosis of an ASD has also been shown to lead to lower levels of family harmony

(Perry et al. 2004). This provides a further layer of challenge for families to make sense of and accept the child's condition.

Adaptation to ASD as Distinct from Other Developmental Disabilities: Behaviour and Communication

Another factor that affects the adaptation of the family to a diagnosis of autism is the unique social, behavioural and communicative deficits in these individuals that affect the family, and in turn the child's relationship with other family members (Meadan et al. 2010). The child's unusual patterns of behaviour, repetitive and restricted interests and routines and challenging behaviours can impact the whole family system and have a profound effect on the adaptation process. Given the greater complexity, unpredictability and inexplicability of autism over other developmental conditions, it has been shown that the family is at higher risk for poor psychological adjustment (Bebko et al. 1987; Morgan 1988; Rodrigue et al. 1993). Bebko et al. (1987) found that in comparison to families of children with other disabilities, families of children with autism experienced greater disruption of family functioning, more upset and disappointment about the child with the disability, and reported participating in fewer recreational activities and vocational opportunities due to the nature of their child's condition.

A further complicating factor for family adaptation to children with a disability is that many exhibit challenging behaviours that can be unpredictable and difficult to manage, which can contribute to family stress. Given that behavioural difficulties are a core impairment in autism (McClintock et al. 2003), and that behavioural disturbances in children with autism are more complex and severe than in other developmental disorders (Eisenhower et al. 2005; McClintock et al. 2003; Morgan 1988; Noterdaeme et al. 2002), it is not surprising that this area brings particular challenges to families of children with this condition. In his research review, Bailey (2007) reported that most studies analysed showed that positive family adaptation is much more difficult to achieve when children exhibit a high rate of behaviour problems. There is considerable evidence that problematic behaviours in children with autism negatively impact parental wellbeing (Morgan 1988; Seltzer et al. 1997) and the sibling relationship (Greenberg et al. 1999; Orsmond and Seltzer 2007; Seltzer et al. 1997). The added burden of challenging behaviour makes adaptation to ASD in the family especially complex.

Numerous research efforts have examined family stress and adaptation in autism in comparison to families of children with other developmental disabilities and to families of typically developing children (e.g. Bouma and Schweitzer 1998; Dabrowska and Pisula 2010; Dunn et al. 2001; Eisenhower et al. 2005; Fisman et al. 1989; Perry et al. 2004; Rivers and Stoneman 2003; Rodrigue et al. 1990; Sanders and Morgan 1997). The literature has had a focus on parental depression, marital stress, the quality of the sibling relationship, and similarities and differences in siblings' experiences and view of their sibling with the disability. There is much inconsistency in the literature, with some studies reporting negative outcomes for families of individuals with autism (e.g. Kaminsky and Dewey 2001; Knott et al. 1995), others reporting no difference in psychopathology and stress levels for families of children with ASD in comparison to those of children with other disabilities (e.g. Hastings 2007; O'Kelley 2007), and still others finding that families of children with ASDs have some positive outcomes (e.g. Kaminsky and Dewey 2001).

Adaptation of Parents to Having a Child with ASD as Distinct to Other Developmental Disabilities

Much of the research that has focused on parent adaptation suggests that parents of children with ASD experience significantly more stress than parents of children without disabilities and parents of children with other disabilities (e.g. Bouma and Schweitzer 1990; Dabrowska and Pisula 2010; Dunn et al. 2001; Eisenhower et al. 2005; Fisman et al. 1989; Perry et al. 2004; Rivers and Stoneman 2003; Rodrigue et al. 1990;

Sanders and Morgan 1997). Mothers have also reported less perceived parenting competence, less marital satisfaction, and higher levels of depression than mothers of children with typical development or Down syndrome (Fisman et al. 1989; Rivers and Stoneman 2003; Rodrigue et al. 1990). Less work has been done with fathers, although Fisman et al. (1989) also found that fathers of children with ASD experienced more stress and reported less marital intimacy than fathers of children with Down syndrome or typical development. Rivers and Stoneman (2003) found that marital stress was an important predictor of the quality of not only the marital relationship, but also the sibling relationship, such that when marital stress was greater, siblings reported less satisfaction with the sibling relationship, as well as more negative and fewer positive behaviours directed towards their sibling with autism. This research indicates that family systems and the complex interplay of relationships and interactions between family members impact the adjustment and adaptation process. Despite the challenges presented to families raising a child with ASD, some literature suggests that having a child in the family with a disability can present opportunities for growth, challenge, and satisfaction and can promote a sense of self-efficacy to enhance family functioning over time (Blacher et al. 2007; Frain et al. 2007). Furthermore, some parents report that their marriage has been strengthened by the addition of a child with special needs (Blair 1996). This lends support to the models of adaptation that stress the importance of cognitive appraisal in the adjustment and adaptation to having a child on the autism spectrum.

Adaptation of Children to Having a Sibling with ASD as Distinct to Other Developmental Disabilities

Kaminsky and Dewey (2001) found that relationships between children with ASD and their typically developing siblings were marked by less intimacy, prosocial behaviour, and nurturance than sibling relationships that include a child with Down syndrome or typically developing sibling pairs. In comparison to siblings of children with Down syndrome or typically developing siblings, sibling pairs including a child with ASD reportedly spent less time together, and their initiations (both prosocial and antagonistic) were lower in frequency and variety (Knott et al. 1995).

Other research, however, has shown that behavioural adjustment of the typically developing sibling is not affected by the diagnostic category of their sibling's developmental disability. In a longitudinal study by Hastings (2007) comparing the behavioural adjustment of siblings of children with autism, Down syndrome and mixed aetiology mental retardation, no group differences were found in behavioural adjustment of siblings across the diagnostic categories. Further, no evidence was found to support a bidirectional temporal relationship, suggesting that children with developmental disabilities did not appear to be affected by the behavioural adjustment of their typical sibling. Other studies have also failed to uncover differences in adjustment between siblings of children with autism compared to siblings of children with Down syndrome (e.g. O'Kelley 2007).

In an attempt to understand the impact of having a brother or sister with a disability, McHale et al. (1986) interviewed siblings of children with autism, siblings of children with Down syndrome and siblings of typically developing children about their relationship with their sibling, and also interviewed mothers about the sibling relationship. Both siblings of children with ASD and siblings of children with Down syndrome reported a greater admiration of their special needs sibling, and less quarrelling and competition than typical sibling pairs. Based on sibling reports, McHale et al. (1986) found no group differences in the quality of the sibling relationship, however, mothers of children with ASD and those with children with Down syndrome rated their children's sibling relationships more positively than did mothers of typically developing children. Roeyers and Mycke (1995) interviewed children with a sibling with ASD, Down syndrome or typical development about their sibling relationship, and found that there was a trend for children with a brother or sister with a disability to rate their relationship with the sibling more positively.

Interestingly, positive adjustment outcomes in siblings have been found to be strongly associated with the typically developing sibling's coping strategies, not the severity of the child's disability (Macks and Reeve 2007). In their study of adjustment in siblings of children with autism, Macks and Reeve (2007) concluded that adaptive versus maladaptive adjustment was directly related to the presence or absence of demographic risk factors. They found that having a sibling with an ASD appeared to enhance the psychosocial and emotional development of the typically developing sibling when demographic risk factors were limited; however, having a sibling with an ASD had an increasingly unfavourable impact on the sibling relationship as demographic risk factors increased (Macks and Reeve 2007). Interestingly, McHale et al. (1986) found that positive relationships between children with developmental disabilities and their typically developing sibling were reported when the typically developing sibling (a) accepted the child's role as a member of the family; (b) perceived minimal parental favouritism; (c) had no worry about the future of their sibling; (d) had well-developed coping abilities; (e) understood the sibling's disability and (f) perceived positive responses from parents and peers towards their sibling. This suggests that siblings' understanding and appraisal of the situation and their coping abilities, seemingly in addition to reduced demographic risk factors, influence their overall positive adaptation.

Family Adjustment to an ASD Diagnosis

Parent Adjustment

The majority of ASD diagnoses are made in the early years of childhood. Parents play a key role in initiating the adaptation process following a diagnosis of autism in the family. It is well documented that stress and burden for parents is elevated in the period surrounding initial diagnosis (Bristol 1987; Howlin and Asgharian 1999), perhaps sensitising parents to mobilise existing coping resources. Many studies examining parental stress and burden in the early stages of diagnosis have been retrospective and have relied on recall of parents regarding their stress levels at the time (Stuart and McGrew 2009). These recall periods have ranged from 1 to 10 years, which influences the reliability of the findings given the impact of recall bias and the fact that families, through the adaptation process across time, will have altered their appraisal about the initial and ongoing impact of the stressor in their lives. Given the crucial role that parents play in the adjustment and adaptation process, it is necessary to understand the factors that impact families following a diagnosis of ASD.

In an attempt to clarify these stressors on families, Stuart and McGrew (2009) studied the application of the Double ABCX model of family adaptation to caregiver burden in ASD in a concurrent research design. Seventy-eight primary caregivers of children diagnosed with ASD within the previous 6 months participated in the study. The variables studied through the Double ABCX model included: severity of the family member's diagnosis (A), pile-up demands and additional life stressors (Aa); the family's internal resources (e.g. internal locus of control) (B); the family's external resources such as social support and finances (bB); the family's appraisal of the situation as either positive or negative (C); and the coping strategies used (cC) as predictors of the outcome in terms of caregiver (individual, marital and family) burden (X). The Double ABCX model accounted for 81 % of the variance in individual burden and 77 % of the variance in family burden. Caregiver burden (X) was found to be consistently and strongly predicted by autism symptom severity (A), additional pile-up demands (aA), social support (bB), negative appraisal of caring for a child with ASD (C); negative appraisal of the diagnostic experience (C) and the use of passive avoidant coping strategies (cC; Stuart and McGrew 2009).

Much of the cross-sectional research literature employing group designs indicates that parents of children with mental retardation, ASD and other developmental disorders report greater levels of stress and more mental health problems than parents of typically developing children

(Hastings 2007; Quintero and McIntyre 2010). Indeed, mothers of children with ASD report more daily hassles, life stress and depression to mothers without a child with ASD (Quintero and McIntyre 2010). The research literature on parental depression and stress has consistently demonstrated negative outcomes for parents of children with ASD (Quintero and McIntyre 2010).

Hastings et al. (2005) noted that much of the previous research into family adaptation has viewed the child's autism as being the stressor and the family members' wellbeing as being the outcome. However, they proposed a more systemic conceptualisation whereby all family members interact and impact on each other. They evaluated 48 mothers and 41 fathers of pre-school age children with autism to explicitly examine relationships between child, partner and parent variables. They found that mothers reported more depression. However, they also reported more positive perceptions of the child with ASD and their impact on the parent and the wider family compared to fathers. Regression analyses revealed that maternal stress was predicted by their child's behaviour problems (not adaptive behaviour or autism symptoms) and by their partner's depression. Paternal stress and positive perceptions were predicted by maternal depression (Hastings et al. 2005). This adds weight to the notion that family interactions are bidirectional and that a systemic approach to researching outcomes is essential to understanding the adaptation process.

Longitudinal research designs have been an important recent addition to the research on the impact of child behaviour problems on parental wellbeing in the general parenting literature. The results of these studies demonstrate a bidirectional relationship between childhood behaviour problems and parental wellbeing (Hastings 2003b). Lecavalier et al. (2006) have demonstrated that, like families of typically developing children, this temporal relationship exists for families with children with ASD as well.

More recent attention has focussed on the trajectories of emotional wellbeing for mothers of adolescents and adults with ASD. In their ongoing longitudinal study of emotional wellbeing of mothers, Barker et al. (2011) found that maternal depression remained relatively stable across the 10-year period of examination with older mothers reporting fewer depressive symptoms at the beginning of the study compared to younger mothers; whereas anxiety declined across the 10-year period with older mothers reporting less anxiety at the start. Barker et al. (2011) argue that this is evidence of resilience, that is, positive adjustment in the face of exceptional stress.

Importantly, in terms of considering early intervention and family support needs, maternal stress and child behaviour problems seem to persist across time. A 2-year longitudinal study conducted by Peters-Scheffer et al. (2012) of 104 mothers of children (aged 2–9 years) with ASD and mental retardation found that maternal stress as measured on the Parenting Stress Index (PSI; Abidin 1995) remained stable across time. Emotionally reactive behaviour, withdrawn behaviour and attention problems of the child significantly predicted maternal stress and these behavioural problems also remained stable across time. This is consistent with previous research that has found that behavioural problems significantly contribute to parental stress and this transaction is bidirectional (Lecavalier et al. 2006).

Exclusive focus on family functioning as an outcome fails to recognise the transactional interplay of child and family factors over time (Sameroff 2009). Although some authors argue that the neurodevelopmental deficits in autism limit the extent to which family factors may be able to modify the behavioural phenotype (see Baker 2010 for a discussion of biological constraint theories), there is growing evidence that parenting can influence autism-related behaviour even if this behaviour is largely neurobiological in etiology (Baker et al. 2011). A family's ability to adapt, that is, to remain flexible, to reorganize around new challenges and to develop collaborative and cooperative problem solving is likely to enable individual family members to adapt to the many challenges of family life (Baker et al. 2011), including the unique challenges facing families with a child with ASD. Family level adaptability has been found to predict changes in severity of maternal depression and child behaviour problems 3 years later in families with a child with ASD aged between 10 and 22 years (Baker et al. 2011). However, it may be that the developmental life stages of both the child and the family may account for some of these changes across time.

Greater attention has been paid to the impact of an ASD diagnosis on mothers than fathers possibly because of the ease of access researchers have to mothers. This is a major oversight in the literature and severely disrupts our efforts to predict service and intervention needs of all family members, especially fathers. Indeed it is proposed that fathers require the same information regarding their child's disability, the same access to resources, programmes, services and treatment as do mothers (Seligman and Darling 2007), however, they may be inadvertently disregarded by service paradigms aimed at mothers.

Grandparent Adjustment to ASD

To the authors' knowledge there are no examinations of the impact of an autism diagnosis in the family on grandparents. This is an important issue for practitioners and researchers alike, as many families find that the cost of interventions to assist their child with ASD necessitates both parents earning an income, often leaving grandparents as the primary caregivers. Additionally, due to the broader autism phenotype and the genetic nature of ASDs, sometimes the child's parents have significant disabilities themselves and so grandparents are carers for their adult child and also their grandchildren with disabilities. The general disability literature acknowledges that grandparents will experience grief and stress reactions similar to the parents of the child with the disability but have the added burden of concerns for the future for their own son or daughter who is now struggling with parenthood (Seligman and Darling 2007). Reactions of grandparents can either mitigate or increase stressors placed on families and further research into these factors is critically required. Interestingly, Konstantareas (1991) proposed that the Double Helix ABCX model of family adaptation could be vertically expanded by incorporating Bronfenbrenner's (1979) social ecology model to consider the contribution of the microsystem (i.e. the family), the mesosystem (i.e. the various social groups with which the family interacts, such as the extended family) as well as the ecosystem (i.e. societal institutions indirectly involved with the family such as health services and early intervention services) and the macrosystem (i.e. the ethnic, cultural, religious and other values as they influence perceptions of and reactions towards disability). This is an interesting proposal, as it would enable the examination of factors external to the family that can be considered as resources and support variables in many of the current models of family adaptation. Family cultural factors may also impact the adaptation of the family to having a child with ASD, particularly in terms of the appraisal of the impact of having a child with ASD in the family. Further exploration of the transactional nature of these factors is required in the research literature.

Sibling Adjustment to ASD

Much attention has been directed over recent years to determining the impact on siblings of having a brother or sister with an ASD and indeed there has been a growing trend towards developing support services for siblings. Like the research into parent and family adjustment, findings concerning the effects on children of having a sibling with autism have been inconsistent. Some studies have observed poor adjustment outcomes in siblings of children with autism in comparison to the siblings of children with other developmental disabilities (Fisman et al. 2000). Links between sibling relationship quality and both externalising and internalising behaviours have been found in the general literature on sibling influences (Brody et al. 1992). Research has suggested siblings of individuals with autism experience feelings of loneliness and difficulties with their siblings' behaviour (Bågenholm and Gillberg 1991), externalising and internalising behaviour problems (Fisman et al. 2000; Gold 1993; Rodrigue et al. 1993), and a lack of social reciprocity in sibling interactions (Knott et al. 1995).

Many studies report at least some positive effects (or an absence of negative effects) of the presence of a child with autism on a sibling's adjustment when compared to siblings of typically developing children. In addition to siblings of children with ASD reporting less conflict (Fisman et al. 1996; Kaminsky and Dewey 2001), they also report greater warmth towards their sibling (Fisman et al. 1996) than siblings of typically developing children. A number of studies have found siblings of children with ASD have a positive self-concept (Ferrari 1984; Macks and Reeve 2007; Mates 1990; McHale et al. 1986; Rodrigue et al. 1993) with some studies even suggesting that siblings with a brother or sister with an ASD fare better than siblings of typically developing children (McHale et al. 1986). Overall, siblings of children with autism tend to view their sibling relationships positively (Bågenholm and Gillberg 1991; Kaminsky and Dewey 2001; McHale et al. 1986; Roeyers and Mycke 1995).

In their review of the literature on the social, emotional and behavioural adjustment of siblings of individuals with ASD, Meadan et al. (2010) found inconclusive results on outcomes for and adjustment of typically developing siblings of children with ASD. Overall, they concluded that some siblings are positively affected and have high levels of self-concept and social competence by having a sibling with ASD, while others experience negative effects, including low levels of prosocial behaviour, increased internalising and externalising problem behaviour, feelings of loneliness and delays in the acquisition of socialisation skills. Such findings prompt the need for further exploration into the mediating factors at play to determine what characteristics might inhibit or promote positive adaptation.

A family systems approach to understanding the interrelationships between family members is growing in popularity (e.g. Modry-Mandell et al. 2007). More recent research into sibling adjustment to a family member with a chronic or life threatening illness (Houtzager et al. 2004), disability or ASD has recognized the bidirectional nature of family interactions such that siblings will both be influenced by and influential in their sibling's behaviour and adjustment, as are parents. Additionally, children are influenced by other relationship dynamics within the family. For example, in a review of the general literature on the links between parents and sibling relationships, Furman and Giberson (1995) reported that marital conflict tends to be positively associated with sibling conflict. This finding was replicated by Rivers and Stoneman (2003) in their study of 50 families with a child with autism. Similarly, a study by Brody et al. (1992) found that marital conflict and less cohesive family dynamics were associated with less prosocial and more antagonistic behaviour between siblings. Perhaps not surprisingly, researchers have also demonstrated that a more positive parent-child relationship is associated with greater positive sibling expression of affect (e.g. Stocker et al. 1989; Kramer and Gottman 1992). These findings highlight the impact of family dynamics and family adaptation on individual relationships, in this case, the sibling relationship. They underscore the importance of considering the family dynamics in understanding family adaptation.

The behavioural presentation of children with autism can also put a strain on the sibling relationship. The traditional absence of imitation, functional play and imaginative play that is a common deficit in ASD may make it difficult for the typically developing sibling to engage with their preschool brother or sister with ASD (Ferraioli and Harris 2009). Children with ASD also have a limited repertoire of play and social skills, poor eye contact, communication difficulties and low social responsiveness (Knott et al. 1995; Sanders and Morgan 1997), further hampering their ability to develop these early connections with their siblings through socialisation and interaction which are so critical to social development in the early years.

Additionally, it is possible to speculate that the stress of having a child with ASD within the family may significantly impede sibling relationships and contribute to greater emotional stress on parents such that marital relationships and sibling adjustment is compromised. As children with developmental difficulties exhibit a greater magnitude of behavioural problems and mental health problems compared to typically developing children (Hastings 2007), it has long been considered that siblings with a brother or sister with mental retardation or ASD would be adversely affected. However, in a recent meta-analytic review Yirmiya et al. (2001) concluded that the research evidence fails to provide sufficient evidence that siblings of children with ASD are at increased risk for negative psychiatric outcomes. In contrast, Rossiter and Sharpe (2001) conducted a metaanalytic review of 25 studies and concluded that there was a small negative effect of a child with mental retardation on sibling adjustment. It is possible that the intellectual ability of the child with an ASD may serve as a protective factor when it comes to the impact on siblings. In a comparison of siblings of children with High Functioning Autism (HFA) compared to those with typically developing siblings, Verté et al. (2003) reported no overall greater susceptibility to adaptation problems than siblings of children without a disability.

Macks and Reeve (2007) conducted a cross-sectional study to examine the impact of having a sibling with a developmental disability on the psychosocial and emotional adjustment of siblings. They reported enhanced psychosocial and emotional development for those children with a sibling with a developmental disability compared to those without. However, this was true only if demographic risk factors (such as male gender, low socio-economic status, only having one sibling, and being older than the child with autism) remained minimal. As these risk factors increase, the impact on siblings becomes less favourable (Macks and Reeve 2007).

Hastings (2007) conducted a longitudinal study of 75 siblings of children with mental retardation and other diagnoses looking at the relationship between sibling adjustment and behaviour problems of children with developmental disabilities. Interestingly, he found no evidence of group differences between those whose siblings were diagnosed with autism compared to mental retardation or Down syndrome. Additionally, he found that the behavioural problems of the child with ASD at the time of recruitment to the study, and not those changes across time, predicted sibling adjustment. There was no evidence that this relationship was bidirectional such that sibling adjustment did not appear to impact the behavioural difficulties of the sibling with ASD across time.

Research on sibling adjustment at home and at school has been inconclusive with some studies reporting an increased risk for siblings in terms of adjustment and school achievement while other studies report instances of siblings adjusting well and performing above expectations in terms of academic and other achievements (Mates 1990). McHale et al. (1986) compared sibling relationships between typically developing siblings and their autistic, mentally retarded or non-disabled pair. Thirty siblings from each group were matched on age and gender. McHale et al. (1986) examined mothers' reports of the sibling relationship as well as the siblings' report of their relationship with their brother or sister. They found that while there was less family cohesion and less involvement in family activities of the child with disabilities, the mothers of children with a sibling with developmental disabilities rated their child more positively on acceptance, support, hostility and embarrassment than those mothers without a disabled child in the family. Importantly, McHale et al. (1986) noted that the range of responses were greater within the handicapped groups with some responses of the disabled group falling at the two extremes. That is, some of the siblings were functioning extremely well while others were struggling with the impact of having a brother or sister with a developmental disability. Other studies by Abramovitch et al. (1987) and Lobato (1985) noted that siblings of children with disabilities tended to be more nurturing and prosocial towards their siblings compared to normally developing siblings, suggesting positive developmental outcomes for siblings of children with ASD. However, in a study of 22 siblings of children with ASD (aged 7 to 16 years), Hastings (2003a) examined the adjustment of siblings by having mothers' complete the Strengths and Difficulties Questionnaire (SDQ; Goodman 1997). He found that siblings were rated by their mothers as having more behaviour problems and less prosocial behaviour than a normative sample. Interestingly, he noted that boys with a sibling with an ASD and those younger than their sibling with ASD engaged in less prosocial behaviour. It may be that younger siblings' behavioural difficulties are amplified by mothers in their responses to questionnaires due to the stress of having an older child with an ASD. It is also possible that younger siblings struggle to learn prosocial behaviour when they do not have adequate role modelling by an older sibling and have limited parental resources and attention due to having a child with an ASD in the family. Interestingly, in their study of older siblings (6 to 10 years of age) of children with an ASD, Quintero and McIntyre (2010) reported that there were no significant differences in parent or teacher reports of siblings' social, behavioural and academic adjustment compared to families without a child with ASD. This suggests that the age of the sibling and the associated life stage are important factors in understanding the adjustment of siblings and the perceived difficulties of sibling adjustment reported by parents. Importantly, Hastings (2003a) also found that maternal stress and behavioural difficulties of the child with an ASD were not predictive of sibling behavioural adjustment.

There are considerable methodological problems inherent in this research. For example, siblings may be older or younger than the child with ASD with varying age gaps of months to years. The life stage of the sibling, while likely to contribute significantly to adjustment, has generally not been taken into account (Orsmond and Seltzer 2009). Additionally, gender differences between siblings may impact family adjustment or indeed perceptions of family adjustment. Research on siblings of a child with mental retardation indicates that female siblings and siblings from two-child families are at greatest risk of poor adjustment (Cleveland and Miller 1977; Farber 1959; Farber and Ryckman 1965; Fowle 1968; Gath 1973, 1974; Lobato et al. 1988). However, Mates (1990), in his examination of the adjustment of children with autistic siblings, found that there was little variance as a function of gender or family size.

Given the gender differences between rates of externalising and internalising behaviours, it is possible that gender differences are impacting family functioning and this requires further exploration. Additionally, it is not possible to randomly assign young people to being in a family with a sibling with ASD, so randomized controlled trials that allow the control of extraneous variables are not possible. Any number of other factors, unrelated to the child with ASD in the family may be contributing to the impact on the family's coping resources and responses (Hastings 2007). Interestingly, siblings of children with an ASD have a greater genetic vulnerability for having some autistic characteristics while not meeting full criteria for an ASD. As such, while siblings selected for evaluation in terms of impact may not have been diagnosed as having an ASD, they may have some autistic features that are subclinical yet impact their responses to both their interactions with their sibling as well as their responses to research questions. This is understood as the 'broader autism phenotype' (Bauminger and Yirmiya 2001), and may contribute to increased vulnerability of these siblings.

Early Intervention (0–6 years): Implications for Intervention with Families

Roberts and Prior (2006) completed a review of the international literature, to provide guidelines for best practice for early intervention programmes for children with ASDs. The authors concluded that children who received intervention in the earliest stages of development (optimally between 2 and 4 years) would achieve the best outcomes as this critically important time for learning powerfully affects their developmental trajectory (Roberts and Prior 2006). They also concluded that to be successful, early intervention should be intensive, with at least 20 hours per week over 2 or more years for optimal outcomes for young children with autism. The authors stressed that no one intervention would work for all children and families, due to the nature and complexity of ASD, and the degree of variation in individuals along the spectrum. They concluded that programmes that are delivered early, are intensive, and are family based will be effective for children with ASD as long as these are adapted to the child's individual pattern of strengths and weaknesses and take into account family circumstances (Roberts and Prior 2006).

The review highlighted a number of key elements that are essential for effective programmes. Effective programmes (a) provide autism-specific curriculum content that focuses on attention, compliance, imitation, language and social skills; (b) provide highly supportive teaching environments; (c) include specific strategies to promote generalization of new skills; (d) address the need for predictability and routine; (e) use a functional communication approach in addressing challenging behaviours; (f) support children in their transition from the preschool classroom; and (g) ensure that family members are supported and engaged in a collaborative partnership with professionals involved in the delivery of treatments (Roberts and Prior 2006).

The range of interventions for individuals with autism can be classified in a number of ways. Mesibov et al. (1997) distinguish between biological, psychodynamic and educational. Roberts and Prior (2006) concluded that there was insufficient evidence to support the use of biological interventions (such as medication or complementary and alternative medicine) for children with ASDs. Psychodynamic interventions (such as Holding Therapy and Pheraplay) were also unsupported and given that the evidence suggests autism is a developmental rather than an emotional disorder, such interventions are no longer thought to hold much weight (Mesibov et al. 1997). The review therefore focused on educational interventions which centre around skill development and relationship development, and the authors concluded that intensive educational and behavioural interventions produce the best outcomes in young children with autism (Roberts and Prior 2006).

Educational interventions in the review by Roberts and Prior (2006) were summarized as behavioural (with a focus on skill development, such as Applied Behaviour Analysis); developmental (with a focus on relationship development, such as Relationship Development Intervention); therapy based (with a focus on specific areas such as communication, such as the Picture Exchange Communication System); family based (with a focus on enabling parents to promote development in their children, such as the NAS Early Bird Program in the UK); or combined (programmes that combine one or more of the above, such as Social-Communication, Emotional Regulation and Transactional Support; SCERTS). The authors summarized the evidence supporting each of these in their review (see Roberts and Prior 2006). Results clearly demonstrated that intervening early in a child's life and providing an intensive early intervention programme incorporating the elements listed above resulted in better long-term outcomes for children with autism and their families. Given the intensive nature of early intervention programmes required to achieve the best possible outcomes for the young child with an ASD, it is crucial to consider the additional needs of parents, siblings and grandparents. On the basis of the available research, it is important to assist parents in the initial stages post-diagnosis, as they are the major change agents in assisting the entire family to progress through the adaptation process. Parental mental health and the quality of the marital relationship are important factors in mobilising existing resources. These are often overlooked elements of early intervention as most professionals focus intently on the child with ASD. However, failure to address these factors leaves parents to begin the complex adaptation process on the basis of their own existing resources. Parents require assistance to access additional resources for their own mental health (such as psychological therapy for depression and anxiety; informational support to deal with the grief and shock associated with the initial diagnosis and to understand the diagnosis itself and the ramifications for the child with ASD and the entire family) as well as for their relationship (such as respite care to allow for couple activities; assistance to develop communication and problem-solving skills) to give the couple access to the most effective ways to deal with highly difficult and stressful parenting experiences. Additionally, parents could be aided with the process of appraisal of the situation for themselves and their children so that feelings of guilt, assumptions about inadequate parenting and misattributions for the crisis situation faced by the family can be addressed early in the family adaptation process. This may be achieved through family-based interventions or through group-based interventions where parents and siblings have an opportunity to meet other families experiencing similar challenges. This may assist parents and siblings to move more productively through the adaptation process.

Grandparents could be targeted in early intervention efforts by giving them access to accurate information regarding ASDs and guiding appropriate and helpful responses to parental concerns and needs for support. A great deal more research is required to be able to determine culturally sensitive ways to support grandparents.

Siblings are rarely considered in early intervention programmes. However, it is clear that not all siblings have a positive outcome and they require individualized support. Siblings should be included in routine family needs assessments so that adequate emotional, parenting and educational supports can be implemented. Siblings have also been shown to be capable co-therapists in assisting their siblings to learn and generalize many of the social and independence skills taught in early intervention programmes (e.g. Castorina and Negri 2011). Depending on the developmental age and stage of siblings, parents may require assistance to meet the additional demands to their parenting resources while attempting to attend to the intensive early intervention programme for their child with an ASD. Parent education and support with other children in the family is crucial to addressing the needs and the adjustment of siblings.

In conclusion, early intervention programmes need to consider the entire family as an interactive unit that has both common and unique needs, with these needs varying across the process of adjustment from the initial phase of learning about the diagnosis to ongoing intervention with respect to working through early intervention and addressing ongoing challenges such as emotional and behavioural concerns of the child with ASD as well as other family members.

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Part II
Intervention

Ethical Issues in Early Intervention

8

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Keywords
Ethics

Professionals who provide early intervention services for children with autism (and related conditions) are expected to adhere to the code of ethics promulgated by their discipline. These codes set forth the principles of conduct governing an individual or a group. For example, ethical professional practices for Board Certified Behavior Analysts are outlined in the Behavior Analyst Certification Board Guidelines for Responsible Conduct (BACB Guidelines 2010). These guidelines, like those of other organizations that provide clinical services, such as the American Psychological Association (2010) and the American Medical Association (2012), provide general information about the kinds of actions by professionals and interactions between professionals and clients that are appropriate and, at least as importantly, those that are inappropriate. The former are "ethical," the latter "unethical," and some behavior analysts (e.g., Bailey and Burch 2011) base their consideration of ethical issues entirely on the code of ethics of their profession, specifically the *BACB Guidelines*. Such an approach is certainly practical and the book by Bailey and Burch is an excellent introduction to ethical issues likely to pertain to early interventions for children with autism. We believe, however, that focusing only on the *BACB Guidelines,* or the codes of conducts of other organizations, fails to address adequately some important ethical issues. Therefore, we cast a wider net in the present chapter.

From our behavior analytic perspective, it appears that "ethical" behavior involves patterns of responding that members of a particular culture or subculture, for example, people governed by a professional code of ethics, consider to be particularly important, tact (i.e., label) with the same descriptors (e.g., as "ethical" or "moral," which are functionally equivalent stimuli), and consciously attempt to foster with appropriate rules and consequences. Many decisions regarding early interventions for children with autism can be construed as ethical issues, insofar as they involve deciding whether particular actions that caregivers take with respect to children with autism are labeled by members of the relevant audience as good or bad, right or wrong, ethical or unethical. The problem with this approach in the present context is that many people (e.g., parents, siblings, classmates, teachers, medical doctors,

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speech therapists, occupational therapists, behavior analysts, taxpayers) have a legitimate interest in the interventions arranged for young children with autism, and they will not necessarily agree on the ethical acceptability of particular applications. Although philosophers and psychologists have suggested that there may be universal standards of "ethical" behavior and endeavored to develop models explaining why people do and do not behave "ethically," these efforts have been largely unsuccessful (Rogerson et al. 2011).

Our purpose is to introduce a range of issues concerning early interventions for children with autism that might, but need not, be construed as ethical issues. Framing them as ethical issues draws attention to their importance, but also is apt to generate counterproductive emotional responding. For example, in discussing the evidence for the effectiveness of early interventions, we note that the scientific evidence of effectiveness often is relatively weak. As a case in point, although aripiprazole (Abilify) and risperidone (Risperdal) are approved by the US Food and Drug Administration for treating "irritability" in children with autism, the studies on which approval was based lasted for only 2 months and there are no data regarding the effects of these drugs when taken for long periods beginning early in life. Anyone who prescribes aripiprazole or risperidone as an early intervention for children with autism is making a leap of faith in the hope that doing so meaningfully benefits the children. There is certainly a possibility that the quality of a child's life will be improved substantially by the drug, and that is why the physician prescribes it. But there is also a possibility that a given patient will be harmed in the long run, although the probability that such harm will occur cannot accurately be specified when treatment is delivered. A physician's decision to prescribe or not prescribe aripiprazole or risperidone for a young child with autism who exhibits high levels of inappropriate behavior could be construed as an ethical issue, and she or he could (but in our view should not) be accused of behaving unethically if the wrong choice is made. But what is the wrong choice? The answer, of course, is likely to depend upon whom one asks and our opinion is of no special importance. We are not arbiters of ethical conduct and, save for what should be an unnecessary warning against gross malfeasance or implementing treatments that are clearly harmful or valueless, we make no attempt to dictate which early intervention practices are and are not ethical. We do note, however, that there is much worthy of consideration when the topic is opened to full and fair discussion.

Diagnosing Autism

When we make a diagnosis based on objective underlying differences between people, we are defining "natural kinds" in that the fundamental differences already existed in nature before our classification. We are cleaving nature at the joints, to use a common analogy, when we diagnose a child with Down syndrome because we can point to a chromosomal abnormality that is responsible for the manifestations of the syndrome. In contrast, when we do not have information about a fundamental underlying distinction and make a diagnosis based on social convention with respect to the signs and symptoms of interest, we are not defining "natural kinds" but rather applying a label to a set of characteristics. With autism, there is at present no measurable underlying mechanism that accounts for the symptoms of the condition, and diagnosis of autism is based on a socially defined set of behavioral characteristics, so autism does not fit our definition of a "natural kind." Currently, according to the *Diagnostic and Statistical Manual of Mental Disorders IV-TR*-(*DSM-IV-TR*), if an individual displays restricted, repetitive stereotypical behavior in addition to impairments in both social interaction and communication, she or he may be appropriately diagnosed with autism (American Psychiatric Association 2000). Some of the impairments or abnormalities must be present before 3 years of age. The items that are used to determine if the above criteria are met include such behavioral characteristics as "lack of social or emotional reciprocity," "stereotyped and repetitive use of language or idiosyncratic language," and "persistent preoccupation with parts of objects." In the end, diagnosing someone with autism is a judgment call and there is no "gold standard" for the diagnosis.

Autism is classified as a neurodevelopmental disorder, and there is quite a bit of evidence supporting this classification. For example, a general finding is that children diagnosed with autism often experience unusually rapid brain growth shortly after birth followed by slowed or arrested brain growth at around 2 years of age. The rapid growth appears to occur primarily in certain regions of the brain, such as the temporoparietal region. Other regions of the brain, including the corpus callosum, characteristically are smaller, relative to overall brain size, in children with autism than in typically developing children (Casanova 2007; Polšek et al. 2011). Although knowledge of these neurological differences may be useful in understanding the observed behavioral characteristics of children with autism and may eventually aid in diagnosis and the development of strategies for assisting people diagnosed with autism, they are themselves manifestations of an underlying factor or, more realistically, a constellation of factors that lead to both the neurological and behavioral characteristics of people with autism.

Moreover, recent research strongly suggests that the three behavioral domains characteristic of autism (social impairment, communication difficulties, rigid and stereotyped behavior) are relatively independent (see Happé et al. 2006). That is, there is not a strong correlation between the severity of a child's impairment in one of these areas and her or his impairment in either of the other areas. The independence of the three behavioral domains characteristic of autism makes it highly unlikely that there is a single genetic, biochemical, cognitive, or behavioral explanation that is able to explain the disorder (Happé et al. 2006).

The results of twin studies do suggest that there is a strong genetic component to autism (Muhle et al. 2004; Ronald and Hoekstra 2011), but the possibility that a single gene is responsible for autism has been definitively ruled out (Casanova 2007; State and Levitt 2011). Instead, it appears that a number of genes in combination with environmental factors, including prenatal development, lead to the group of behavioral characteristics we call autism. Children diagnosed with autism are remarkably heterogeneous, and it is becoming increasingly clear that "autism" comprises several subtypes of behavioral deficiencies, which are highly likely to differ in etiology. This point is made clearly by David Amaral, the director of the Autism Phenome Project, which is a large research project designed to "distinguish among subgroups or phenotypes of autism [and] link these different forms of autism with distinct patterns of behavior and biological changes" (UC Davis MIND Institute 2012):

> One of the major stumbling blocks of understanding autism is that it's incredibly heterogeneous. Some kids with autism have severe developmental delays, but others have normal or even enhanced I.Q.'s; some have epilepsy, mental retardation, or gastrointestinal problems. You are looking at kids who have very different biological and comorbid features, but all are under the umbrella of autism spectrum disorders. The goal of this project is to identify subtypes of autism. Once we identify those, we believe that we can go after the cause for each one in a more productive fashion. It is almost certain that autism has multiple causes, and it might be better to study each one independently. (Goehner 2012)

While it may be tempting to think of the individual diagnoses that are currently placed under the umbrella of "autism spectrum disorders (ASD)" (autism, Asperger syndrome, and pervasive developmental disorder, not otherwise specified) as separate disorders arising from distinct genetic abnormalities, this is a naïve viewpoint with no scientific support. At present, determining which label to apply to a child presenting with behaviors characteristic of autism is like cleaving meatloaf at the joints, although this may change if the Autism Phenome Project bears fruit.

Because autism is not a "natural kind," the behavioral characteristics in the diagnostic algorithm and the number of characteristics in each category required for diagnosis can change. The changes to the new *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-V*) (American Psychiatric Association 2013), which may well restrict the range of individuals diagnosed with autism (or related conditions) and therefore limit the services that some people receive, have met with fierce opposition by those who want to maintain the status quo, and it appears that this opposition has affected the decisions of the DSM Task Force charged with revising the diagnosis of autism and related conditions. Be that as it may, DSM V no longer differentiates “autism” (or “autistic disorder”), “childhood disintegrative disorder,” and “pervasive developmental disorder not otherwise specified,” but instead groups these disorders under the collective classification of “ASD.” Given the difficulties in distinguishing among the previously recognized disorders, this appears to be an appropriate change, although as noted previously, ongoing research may well reveal differences among children with “ASD” that are readily distinguished and both conceptually and clinically significant.

A change that may be even more significant is reducing the three domains characteristic of autism (or autism spectrum disorder) to two, “social/communication deficits,” and “fixated interests and repetitive behaviors.” The new language appears in Table 8.1. Three levels of severity of ASD are recognized. Level 3, “requiring very substantial support,” level 2, “requiring substantial support,” and level 1, “requiring support.” It remains to be seen how changes in the diagnostic categories and criteria that eventually appear in *DSM-V* will affect the lives of people with special needs, that is, the ethical implications of those changes. Interestingly, the DSM Task Force indicates that “requiring two symptom manifestations for repetitive behavior and fixated interests improves specificity of the criterion without significant decrements in sensitivity.” One wonders, sensitivity and specificity relative to what standard?

The *DSM-V* language describes ASD as a neurodevelopmental disorder that “must be present from infancy or early childhood, but may not be detected until later because of minimal social demands and support from parents or caregivers in early years.” In actuality, neuronal structure or function is irrelevant to the diagnosis of the disorder, which is based purely on the basis of behavioral characteristics, and such structural or functional deficits are rarely if ever detected in diagnosed individuals, either early in life or subsequently. Instead, they are simply inferred, which is reasonable but not especially informative. Moreover, specifying that evidence of neurodevelopmental impairment at one point in life is evidence that such impairment was present earlier in life makes the requirement that ASD “must be present from infancy or early childhood” practically meaningless and of no diagnostic value.

Behaviors characteristic of autism appear to be normally distributed throughout the population (Constantino and Todd 2003; Hoekstra et al. 2007), meaning that most people display a few of the behaviors (i.e., the center of the distribution), a few people display none of them (i.e., one tail of the distribution), and a few people display all of the them (i.e., the other tail of the distribution). Put differently, autism represents one end of the spectrum of typically occurring behavior. From this perspective, essence of diagnosis is determining where the line separating “autistic” from “not autistic” should be drawn. Currently, the line is situated in such a way that about 1.1 % of the population falls on the “autistic” side of the line (Center for Disease Control and Prevention 2012). In a normal distribution, this point is about 2.3 standard deviations from the mean.

The ethical implications of moving the cutoff line in either direction are important and should be considered carefully before decisions about changes in diagnostic criteria are made. Members of advocacy groups, such as Autism Speaks, appear to be in favor of moving the cutoff line closer to the mean, but others argue that autism is diagnosed too liberally and that the line should be moved away from the mean. It should be noted that any discussion of “overdiagnosis” is irrelevant in the context of a socially defined disorder such as autism, but concerns about applying the label too frequently may be justified on other grounds. As noted previously, there is no “gold standard” for identifying autism and it is meaningless to talk about the sensitivity or specificity of particular diagnostic techniques. It is, however, highly meaningful to talk about the practical implications of applying those techniques.

When a child is diagnosed with autism, the world from the child’s perspective can change

Table 8.1 DSM V criteria for diagnosing autism spectrum disorder

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history	
1.	Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions
2.	Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication
3.	Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative paly or in making friends; to absence of interest in peers
B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text)	
1.	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases)
2.	Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day)
3.	Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest)
4.	Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement)
C. Symptoms must be present in the early developmental period (but may not become fully manifested until social demands exceed limited capacities, or may be masked by learned strategies in later life)	
D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning	
E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level	

dramatically. She or he might be immediately placed in an early intervention program or begin working with a therapist in the home. It is hard to imagine how these changes would be detrimental, even if the child is "misdiagnosed." Indeed, a compelling argument could be made that *any* child would benefit from appropriate early interventions building on her or his behavioral strengths and remedying any weaknesses. Early intensive behavioral interventions (EIBIs) for children with autism are often characterized by intensive, individualized instruction, with a high instructor to student ratio. Such conditions are apt to maximize the full potential of anyone exposed to them.

If a child is old enough to attend school when the diagnosis of autism occurs, he or she will most often be placed in a special education classroom, sometimes one specifically geared toward children diagnosed with autism (White et al. 2007). One potential disadvantage of children being exposed to such alternative education is that special education comes at the cost of typical education (Dunn 1968). That is, children receiving early intensive educational services are not exposed to the same environment as their typically developing peers experience and may become "atypical" as a result of the atypical educational environment. "Atypical" in this sense is not necessarily bad, but it is imperative that children educated under special circumstances have the opportunity to develop appropriate social skills and adaptive behaviors and to ensure that desired responses developed through early atypical interventions generalize to other situations.

Another issue that is particularly relevant to individuals who are, or will become, verbal (in the traditional sense of the word), is the effect of the label, "autism," on the individual. Although the reasons are not entirely understood, labels appear to have a strong influence on human behavior. A child who is told that she has dyscalculia may never attempt to improve her math skills and may indeed appear to have a disability, even if there were no grounds for the diagnosis. None of us was born with the ability to solve complex math equations, just as none of us was born with a repertoire of culturally defined social graces. Clearly, many individuals who have been diagnosed with autism are not able to learn social skills as readily as their typically developing peers, and some cannot reach a comparable skill level regardless of the amount of time invested. The diagnosis of autism is invaluable if it affords access to services that increase the likelihood of skill development, but the label itself may also affect social behavior. As Orsini (2009) observed:

> Calling a quark a quark makes no difference to the quark [Hacking 2000, p. 105]. Such is not the case with autism. Autistic labels, characterizations, or classifications have a 'looping effect' on autistic people, on non-autistics, and on the ways in which we understand the autistic descriptor. (p. 126)

The influence of the label on people deeply concerned with the child who has been diagnosed as "autistic" is especially important. When parents first hear the diagnosis, "autism," a wide variety of reactions can ensue. Some feel as if they have lost the child, and others feel relieved that they have found the reason for their difficulties in raising the child. Regardless of the specific reaction, it is unlikely that the parents will ever treat their child the same as they did before the diagnosis or the same as his or her siblings. Some likely changes in parenting behavior are appropriate and generally advisable, such as enrolling the child in early intervention programs and focusing on communication skills. But it is possible that the parent may use the label to explain and in a sense excuse inappropriate behaviors as stemming from autism, rather than recognizing that the inappropriate behaviors are the reason for the diagnosis of autism and can be changed in desirable ways. Changes in the behavior of siblings, educators, and peers who have learned of the diagnosis can also have a major impact on the child diagnosed with autism. It is almost as if the act of diagnosing a child with autism places her or him in an entirely different world. Determining whether that world is better or worse for the child is the crux of ethical diagnosis and treatment.

Increased Prevalence of Autism

In the USA and many other affluent countries, the number of people diagnosed with autism has increased rapidly in recent years. This accelerating trend, although alarming, may not be due to an actual increase in the number of people who exhibit behaviors characteristic of autism, but rather to changes in diagnostic practices and other social influences, and studies suggest that changes in diagnostic criteria, average age of diagnosis, accuracy of diagnosis, cultural practices, and awareness of autism account for much of the increase (King and Bearman 2009; Matson and Kozlowski 2011). It is unclear how much, if any, of the upward trend is due to an actual increase in the prevalence of the behaviors that define autism. Therefore, practitioners should be wary of any claims that the "autism epidemic" is anything other than a shift in social and diagnostic practices until there is evidence to support such claims.

Interestingly, recent studies have found that children born in areas associated with high rates of autism have a higher probability of being diagnosed with autism than children born in otherwise similar areas (Liu et al. 2010; Mazumdar et al. 2010). These studies examined the possibility that the effect is due to factors such as viral transmission or environmental toxicity, but the data suggest that the effect is due instead to social factors. For example, Liu et al. (2010) found that "when two children displayed the same level of autism symptoms, the one who lived closer to a child with autism was more likely to be subsequently diagnosed with autism, while the other was more likely to be diagnosed with sole [mental retardation]" (p. 8).

Children who are diagnosed with autism may receive services that differ substantially from the services provided for children diagnosed with mental retardation. If local cultural norms have a major influence on diagnostic decisions and, as a consequence, the services to which children with special needs have access, labels such as "autism" and "mental retardation" may be less effective at grouping children with similar behavioral characteristics and ensuring that they have access to interventions with a high likelihood of benefiting them. With diagnoses of autism on the rise, this is an issue of increasing concern. The best course of action may be to focus on each individual's needs and skill deficits rather than making treatment decisions based on the child's diagnostic label.

Such an approach to service provision is often termed "non-categorical," or "needs-based." With this approach, the services that a child receives do not depend on her or his receiving a specific diagnosis, but rather on exhibiting general categories of behavioral impairment and specific difficulties within those areas which are targeted for treatment with appropriate evidence-based treatments (Stein and Jessop 1989). For example, if a child is not acquiring language at a normal pace, rather than attempting to attach a nebulous label to the child, such as autism, and base treatment options on that label, specific language acquisition difficulties would be targeted for change with the best available intervention. This approach avoids the ambiguity associated with all socially defined conditions, it does not involve labeling people, and it focuses attention on the specific needs of individuals. It requires, however, a reconceptualization of developmental disabilities and raises vexing issues regarding which children qualify for services beyond the ordinary in education and elsewhere. As with traditional diagnosis, one important issue regards where the cutoff separating children with "special" needs from those with "ordinary" needs is drawn. A second important issue regards how best to match individuals with special needs with interventions likely to be effective in meeting those needs. In all of the helping professions, matching individuals to appropriate treatments is the crux of ethical conduct. Traditional psychiatric diagnosis falls short in this regard, but it is unclear whether alternative approaches would fare substantially better.

Autism and Comorbid Conditions

Although relevant data are not extensive, it is generally recognized that many people with autism exhibit signs and symptoms that appropriately call for assignment to other psychiatric (or educational) diagnoses (e.g., Leyfer et al. 2006; LoVullo and Matson 2010; Simonoff et al. 2008; Yeargin-Allsopp et al. 2003). For example, Yeargin-Allsopp et al. (2003) reported that 68 % of their sample of 987 children with autism for whom relevant data were available had cognitive impairment, and Simonoff et al. (2008) found that, in a sample of 112 children with autism "70 % of participants had at least one comorbid disorder and 41 % had two or more" (p. 921). Like autism, common comorbid conditions often can be detected early in life (Matson et al. 2011a). It is important that this occur, because if untreated these conditions can adversely affect the child early in life and thereafter. Phobias, for instance, are more common in children diagnosed with autism than in children without this diagnosis (Matson and Love 1990). If these phobias are not detected and treated effectively early on, they may be inadvertently strengthened and become both debilitating and difficult to eliminate when treatment is eventually implemented.

Given the high prevalence of other distressing conditions in people with autism and the potential value of early interventions for treating these conditions, it is important that screening devices used for the early detection of autism make provision to detect significant comorbidities. Matson et al. (2011b) make this point clearly in a review of instruments for the early detection of autism:

> [I]nstruments should go well beyond measuring core symptoms of autism. The available research shows a marked overlap between core symptoms of autism, challenging behaviors, and some specific types of psychopathology (e.g., ADHD and anxiety disorders). Tests that cover this broader set of symptoms should be paired with an established measure of developmental milestones. We believe this approach to be best practice for early identification and diagnosis of autism, at this point, given current knowledge in the field. (p. 1323)

We agree. Best practices in a given discipline are ethical practices and the general strategy recommended by Matson and his colleagues has much to recommend it. They suggest that the age range of 17–24 months is appropriate for initially screening for autism, because doing so at an earlier age does not yield reliable results, and also argue that it is inappropriate for all children to be screened for autism. Because parents of children subsequently diagnosed with autism recognize that something is amiss early in the children's lives and pediatricians can also detect marked deficits in early developmental milestones, Matson et al. argue that only children who "evince red-flag variables, or who evince other at-risk variables" (p. 1323) require such specific screening. Taking this tack saves valuable resources and spares parents the agony of contemplating a disability that their child almost certainly does not have.

Autism, Money, and Insurance Coverage

Providing early interventions for children with autism is expensive. For example, early intensive behavioral intervention (EIBI) is extremely costly to implement, and it could be argued that financial resources, which are limited in every society, would be better allocated elsewhere. Given the generally positive findings of most reviews of EIBI (Reichow and Wolery 2009; Sallows and Graupner 2005; Rogers and Vismara 2008; Smith 1999; Warren et al. 2011), however, it can also be argued that providing EIBI to a certain percentage of the population is a sound economic decision in that some children respond well to the treatment, no longer require special services, and in the long run become productive members of society, that is, people who produce more than they consume (Chasson et al. 2007; Jacobson et al. 1998). In such cases, EIBI more than pays for itself.

Moreover, to base treatment decisions purely on financial considerations would strike most of us as unethical. There is within the USA growing acceptance that people with autism deserve to receive effective early (and subsequent) interventions and that the provision of such services should be covered by medical insurance. At the time this is written, 34 states and the District of Columbia have passed statutes requiring insurance coverage of autism (National Conference of State Legislatures 2012). Providing insurance coverage for people with autism raises interesting issues regarding who is to be covered and what kinds of services and service providers are eligible for reimbursement.

It is likely and understandable that parents of young children with special needs will press for those children to be diagnosed with autism, and for caregivers to apply the diagnosis liberally, if a diagnosis of autism provides access to insurance payments affording access to needed services. That is, providing insurance coverage for people with autism may move the cutoff for diagnosis closer to the mean, even if formal diagnostic criteria do not change. In our opinion, this is fine. Many people, including us, believe that it is appropriate for *all* children to receive the best possible services and that it is especially important that children who are at risk for developing significant behavioral deficiencies in any domain receive specialized early interventions designed to meet their needs. As noted, however, meeting these needs is costly and insurance companies will undoubtedly resist the "overdiagnosis" of autism.

Moreover, as the new *DSM-5* rules of classifying people with autism spectrum disorder by level of severity becomes commonplace, one can anticipate that insurance providers will attempt to limit services according to severity. That is, put crudely, more money will be available to provide services for a child with level 3 ASD, the most severe level, than for a child with level 1, the least severe. If this practice becomes widespread, one can anticipate protracted legal battles between insurance companies and representatives of children with special needs over whether those children are properly diagnosed with ASD or another, uncovered condition and, if autism spectrum disorder is the proper diagnosis, whether the level of severity is 1, 2, or 3. The outcome of these battles will establish legal precedent and affect the quality of life of many children with special needs and those who love them.

Advocacy Around the World

Even in wealthy countries, there frequently is resistance to supporting expensive educational (or other) programs designed to benefit a relatively small number of children. An advantage of traditional diagnostic schemes is that they help to unify parents and other caregivers as they advocate for appropriate treatment for their children. Autism advocacy groups, such as Autism Speaks, The Autism Advocacy Network, Autism One, Moms on a Mission for Autism, and Unlocking Autism, have been highly effective in calling attention to autism and in lobbying politicians to provide financial support for autism research and treatment. Although estimates vary widely (see Sharpe and Baker 2009), the USA and other developed countries currently spend enormous sums on providing services for people with autism. Whether sufficient funds are spent on early intervention is open to debate—we would argue probably not—it is clear that much less would be spent if there were no effective advocacy groups. Such groups are essentially nonexistent in resource-poor countries, where autism is rarely diagnosed and seldom treated (Samadi and McConkey 2011).

As Samadi and McConkey (2011) point out, there is very little information about autism in resource-poor countries, and this lack of information has led some writers (e.g., Sanua 1984; Zhang et al. 2006) to the unwarranted assumption that autism is rare in non-Western cultures. What is lacking in such countries is not children with the characteristics that lead to a diagnosis of autism in wealthy countries, but rather sufficient resources to look for, find, and treat those children. As Samadi and McConkey wisely emphasized:

> For those families in low- and middle-income countries who have a child with ASD [an autism spectrum disorder], access to professional support services will be limited. But even so there is a growing recognition of the need for cultural sensitivity in importing knowledge and practices from one culture—such as European nations—into societies with very different cultural backgrounds [Blacher and Mink 2004]. For example, different cultures can have different opinions about appropriate intervention and treatment of children with disabilities [Bailey and Powell 2005]. Hence indigenous research is needed to identify the particular needs of families in nonwestern countries and how information and supports can be better tailored to meet their needs and be respectful of their cultures. (p. 1)

Formation of the World Autism Organization (http://www.worldautism.org) should help to focus worldwide attention on autism in resource-poor countries. Important ethical issues concern the extent to which citizens of wealthy countries should provide financial support for autism diagnosis and treatment in developing countries and the extent to which early intervention specialists should share their skills and knowledge with professionals and laypeople in those countries. Technology, such as teleconferencing, now makes it possible to provide services at a distance, so that, for example, behavior analysts can help to arrange EIBI for children with autism whom they never contact directly. If those children live in resource-poor countries, it is likely that such services would have to be arranged on a pro bono basis. No ethical code requires behavior analysts to work for free, but the possibility of doing so occasionally certainly merits consideration by anyone truly devoted to making the world a better place.

As noted in *DSM-IV* (American Psychiatric Association 2000), the naming of categories based on criteria sets with defining features is “the traditional way of organizing and transmitting information in everyday life and has been the fundamental approach used in all systems of medical diagnosis” (p. xxii). “Autism” is a broad, heterogeneous, even amorphous, diagnostic category. Although widely recognized and useful for focusing attention on the diverse needs of many children, “autism” leaves much to be desired as a diagnostic category. According to the *DSM-IV,* “A categorical approach to classification works best when all members of a diagnostic class are homogeneous, when there are clear boundaries between classes, and when the different classes are mutually exclusive” (p. xxii). None of this is true of autism.

Moreover, as noted previously, from an ethical perspective diagnostic categories are justifiable to the extent that they allow care providers to match patients to effective interventions. Consider, for example, a child who is very thirsty (a symptom) and urinates copiously (a sign). If that child is accurately diagnosed with Type I diabetes, insulin injections are likely to be an effective treatment. If, however, kidney failure is the appropriate diagnosis, then insulin is of no value. From a practical perspective, “autism” is a useful diagnostic category if (a) children who receive this diagnosis are especially likely to benefit from specific interventions that would not benefit children who behave similarly but are not diagnosed with autism and (b) receiving the diagnosis of “autism” affords relevant children access to needed interventions. With respect to behavior-analytic interventions, at least, it appears that the general procedures used to change behavior are similar regardless of the diagnostic labels assigned to clients. There are no “magic bullets” for treating autism, and anyone who makes assertions to the contrary is going well beyond the facts.

We have devoted a good amount of space to issues relevant to diagnosis, an area that may not appear at first glance to be directly relevant to ethics. Our goal has been twofold: First, we want to help parents and practitioners avoid common misunderstandings about the nature of autism and the precision with which the condition can be diagnosed. Second, we want to emphasize the impact that a diagnosis of autism can have on an individual, his or her family, and society in general. The label should be viewed as a rough guide, a sticky note placed above a group of people with some similar behavioral characteristics to emphasize these behaviors, but certainly not as the cause of these characteristics. To be clear, the behavioral differences between most people diagnosed with autism and their typically developing peers are very real, as those who live with autism can attest, but we do people with autism no favor by treating the label as anything more than a label.

Treatment Goals, Risk of Harm, and Ethical Conduct

Poling (1994) argued that ethical interventions are intended to benefit the people who are exposed to them, regardless of the nature of the interventions or the characteristics of the people exposed to them. We agree that this is certainly the case with early interventions for children with autism. Good intentions—that is, focusing first and foremost on the well-being of the child when considering the interventions, if any, to which she will be exposed early in life—is a quintessential part of ethical conduct by the adults who care for and provide services to that child. Interventions intended to serve other purposes merit careful scrutiny, although they are not necessarily unethical.

It is, of course, widely accepted that ethical interventions are intended not just to maximize benefit for those treated, but also to minimize harm. The so-called Hippocratic injunction, to first do no harm (in Latin, *primum non nocere*), has long been an axiom central to the education of medical and graduate students in the helping professions (Smith 2005) and it is clear that behavior analysts and other professionals who offer early intervention services have a fundamental responsibility to not harm their clients or to allow harm to occur under their watch (Bailey and Burch 2011). Occasionally, however, some degree of harm must be tolerated in the short term to reduce overall harm and maximize benefit over the long run. This is the case, for example, when a child is exposed to a painful and debilitating surgical procedure that corrects a cleft palate or a heart defect. As discussed elsewhere (Poling et al. in press; Weeden et al. 2010b), functional analysis (FA) of self-injurious behavior is similar in that participants are allowed to injure themselves under controlled conditions so that the variables responsible for self-injury can be isolated and subsequently manipulated to reduce, or ideally eliminate, such behavior in the participant's everyday environment.

In the seminal study of FA of self-injury, Iwata et al. (1982/1994) took great care to ensure that protections were in place to minimize the risk of harm to participants. Iwata and his colleagues indicated that procedures were approved by a human subjects committee (i.e., an institutional review board), individuals who were at risk of severe physical harm were excluded from participation, and all potential participants received a complete medical exam, with neurological, audiological, and visual evaluations as appropriate "to assess current physical status and to rule out organic factors that might be associated with or exacerbated by self-injury" (p. 199). Criteria for terminating sessions were established through consultation with a physician. The physician or a nurse observed sessions intermittently to assess whether or not termination criteria needed to be adjusted. If termination criteria were met, participants were immediately removed from the therapy room and evaluated by a physician or nurse, who determined whether or not the sessions would continue. After every fourth session, each participant was examined by a nurse. Finally, each case was reviewed at least weekly in both departmental case conferences and in interdisciplinary rounds. Using safeguards such as those arranged by Iwata et al. and limiting the number and length of sessions to the minimum required to provide useful information minimizes harm to participants during FA.

Despite the possibility that harmful behavior will be temporarily reinforced (and thus increased) during FA sessions, it is important to point out that a properly conducted FA does not increase the risk of harm to participants relative to that they encounter in their everyday environment, a point made by Iwata et al. (1982/1994). If it is ethically acceptable for a target behavior to occur outside FA sessions, then the same should be true within such sessions, although safeguards to prevent serious harm might be required. Interestingly, published studies rarely mention such safeguards. Of 116 articles describing the FA of self-injurious behavior recently reviewed by Weeden et al. (2010), nine (7.7 %) described session termination criteria and 23 (19.8 %) described other procedural safeguards for reducing risk to participants.

As Weeden et al. pointed out, it is possible, even probable, that appropriate safeguards to prevent harm to participants were in place in the other studies but were not described. Nevertheless, it is important for those implementing FA procedures to consider the potential importance of having in place structured termination criteria and safeguards to protect individuals engaged in FA. Regardless of the procedure involved, before a young person with autism is exposed to the procedure, ethical researchers and care providers should carefully consider the potential adverse effects of that procedure and take appropriate steps to minimize the likelihood and severity of such effects.

Although punishment, in the technical sense of operant behavior being weakened by its consequences, is ubiquitous in the everyday world, it is noteworthy that prominent behavior analysts, including Skinner (1953) and Sidman (1989), have been critical of the use of punishment to reduce behavior and the use of punishment procedures in education and therapeutic settings is strongly restricted. It is the case, however, that behavior analysts differ widely in their opinions regarding the effectiveness of punishment procedures and the ethicality of using them to reduce problem behaviors. For example, a national survey of the efficacy and ethics of punishment mailed to 500 members of the Association for Behavior Analysis in 2004 (DiGennaro Reed and Lovett 2008) produced results revealing that "the range of opinion among respondents was very large, suggesting that any statements in both the popular media and professional publications claiming that 'professionals' think punishment to be ineffective or unethical (or, for that matter, effective or ethical) are not credible" (p. 65). Nonetheless, respondents generally agreed that punishment should be used only to reduce dangerous behaviors, punishment procedures have more negative side effects and are less effective than reinforcement procedures, and obtaining informed consent and administrative approval are not sufficient ethical safeguards when punishment is used.

Although it is often ignored, as when people content that punishment inevitably has serious side effects, there is a substantial literature dealing with the effects of punishment and alternative methods to treat problem behaviors in developmentally delayed persons, although most of the research appeared more than 20 years ago. For example, Matson and Taras (1989) reviewed 382 relevant studies published from 1967 to 1987 and found that punishment procedures were often effective and no more likely to produce negative side effects than alternative response-deceleration procedures. Despite such findings, in a recent review of punishment as it pertains to therapeutic applications of behavior analysis, Lerman and Vorndran (2002) contend that "further understanding of punishment processes is needed to develop a highly systematic, effective technology of behavior change, including strategies for improving the efficacy of less intrusive procedures and for successfully fading treatment" (p. 431).

It is perhaps worth noting as an aside that punishment procedures and procedures involving negative reinforcement are often grouped together as "aversive" or as "aversive control" operations. There is little to recommend this grouping. Although exposure to punishers and to stimuli that generate escape or avoidance responding (i.e., negative reinforcers) is often, but not inevitably, unpleasant, environmental events that serve as punishers may or may not serve as negative reinforcers and vice versa, and under some circumstances people will avoid or escape from procedures involving positive reinforcement (i.e., positive reinforcement can be "aversive"). Grouping together all punishment and negative reinforcement procedures and considering them as "aversive" is misleading and in our view unfortunate, especially in view of the strongly negative position regarding aversive procedures taken by advocacy groups. For instance:

> The Arc [For People with Intellectual and Developmental Disabilities] and AAIDD [American Association on Intellectual and Developmental Disabilities] *are opposed to all aversive procedures* [italics ours], such as electric shock, deprivation, seclusion and isolation. Interventions must not withhold essential food or drink, cause physical and/or psychological pain or result in humiliation or discomfort. (The Arc 2012)

Depending on how "discomfort" is defined, many early intervention strategies might produce it. For example, it is highly probable that at least some children with autism would indicate that they do not like to attend school or participate in discrete-trial training and they would not do so without inducement. Therefore, these activities, which are clearly intended to benefit the children, are aversive (i.e., the children would escape or avoid them if possible) and produce "discomfort" (because they maintain escape and avoidance responding and are labeled as "unliked," "unpleasant," or "uncomfortable"). Most people, including members of Arc and AAIDD, probably would not consider it to be unethical to require a child with autism to go to school or attend a well-designed training session at home, but this example illustrates the difficulties associated with blanket pronouncements regarding what is and is not proper, that is, ethical, treatment of children with autism or other developmental disabilities. Saying "please don't hit your sister" to a boy who strikes his sibling is punishment if the future probability of hitting is reduced, and so is using a cattle prod to produce the same outcome. That, however, is their sole commonality.

Perhaps unfortunately, the potential abuse of punishment and the negative connotations associated with the term often prevent researchers and practitioners from using what many view as mild and innocuous response-reduction procedures, like saying "No," to reduce inappropriate responses. It is noteworthy that children with autism sometimes prefer response-deceleration procedures with a punishment component to alternative procedures not involving punishment (Hanley et al. 2005), punishment procedures are often effective in treating problem behaviors in children with autism (e.g., Campbell 2003; Matson and Taras 1989), and such procedures often do not produce undesirable side effects (e.g., Matson and Taras 1989). In view of these considerations, categorically refusing all punishment procedures from early intervention programs for all children with autism may do a disservice to some of those children. Ethical treatment requires individualization, that is, considering the goals, probable (and, eventually, obtained) effects, and procedures of alternative interventions being contemplated to benefit a particular child. In some cases, a procedure that can be accurately construed as involving punishment may be the best option for a child with autism. When punishment is used in a technical sense (i.e., as a description of a procedure in which the consequences of a particular response class reduce the probability of occurrence, or otherwise weaken, members of that response class), it is not inevitably unethical (see Cipani 2004). Certainly appropriate safeguards are needed when punishment is used, but the same is, or should be, true of all other behavior-change strategies.

Psychotropic drugs, which are medications prescribed with the intent of improving mood, cognitive status, or overt behavior, are a case in point. Such drugs are commonly prescribed for people with autism, including children (e.g., Poling et al. 2010), and in some cases certainly constitute an early intervention. It is widely recognized that all psychotropic drugs can produce adverse effects, although the nature and severity of these effects differ across medications and are influenced by many variables, including dose and patient characteristics. Risperidone (Risperdal), for example, is an atypical antipsychotic drug approved by the Food and Drug Administration (FDA) for treating "irritability" (which means reducing undesired behaviors such as stereotyped, aggressive, and destructive responding) in people with autism between 5 and 17 years of age (U.S. FDA 2006). The FDA does not regulate the practice of medicine, however, and physicians can and do prescribe risperidone to younger and older people.

Risperidone can produce a range of side effects, including tremors, drowsiness, fatigue, drooling, weight gain, and enuresis (e.g., Ghanizadeh and Kianpoor 2008; Scahill et al. 2007), but it is impossible to predict accurately which, if any, of these effects will appear in a given child. Anyone who supports early intervention with risperidone should be aware that such effects may occur. Moreover, she or he should be certain that provision is made to detect and deal appropriately with these and any other untoward effects that may occur in the course of treatment. Unfortunately, possible adverse effects of protracted exposure to risperidone begin early in life, which is certainly tenable in some cases, have not been evaluated, and it is possible that early intervention with risperidone exposes children to currently unknown risks. Be that as it may, careful consideration of the possible adverse effects of alternative treatments is an important part of ethical care provision. So, too, is careful monitoring to detect such effects. Poling (1994) contended, and we agree, that:

> It is critical that decisions concerning [medication] use are individualized and data-based to the fullest extent possible. Because we can never know *a priori* how a given person will respond to medication, we must always determine what the medication is intended to do and whether this goal is accomplished. Moreover, we must take care to ensure that observed benefits are evaluated relative to real and possible costs to the patient, and that all decisions are made in her or his best interests. If this is done, treatment is rational and ethical as well. (p. 171)

The same points can be made with respect to all interventions, regardless of their modality or whether they are implemented early, late, or at the midpoint of a person's life. The ethicality of early interventions for people with autism do, however, deserve particular scrutiny, because

Table 8.2 BACB requirements for responsible conduct state regarding treatment efficacy

2.10 Treatment efficacy	
(a)	The behavior analyst always has the responsibility to recommend scientifically supported most effective treatment procedures. Effective treatment procedures have been validated as having both long-term and short-term benefits to clients and society
(b)	Clients have a right to effective treatment (i.e., based on the research literature and adapted to the individual client)
(c)	Behavior analysts are responsible for review and appraisal of likely effects of all alternative treatments, including those provided by other disciplines and no intervention
(d)	In those instances where more than one scientifically supported treatment has been established, additional factors may be considered in selecting interventions, including, but not limited to, efficiency and cost-effectiveness, risks and side effects of the interventions, client preference, and practitioner experience and training

children may be unable to object to treatments to which they are exposed, even when they receive no benefit from or harm by those treatments. Greiner (1958) called attention to this issue more than 50 years ago in an early discussion of the use of psychotropic drugs to treat people with what was then termed mental retardation. He wrote:

> Sensible adult patients will usually balk when a drug is causing [negative] symptoms, but the very young and the very old are forced to take drugs, can't complain or stop on toxic symptoms, may not even connect them with the drug. The mentally deficient of any size or age cannot protect themselves either, and they also merit special care to avoid toxic doses. (p. 349)

Young children with autism are a highly vulnerable group. They do not have the capacity to consent voluntarily to early interventions of any type and it is imperative that (a) appropriate proxy consent be obtained before any such treatment is arranged and (b) the effects of any treatment are carefully monitored to prevent injury to and maximize benefit for the child.

Right to Effective Treatment and the Ethics of Evidence

Behavior analysts generally hold that their clients have a right to effective treatment (Van Houten et al.1988) and this belief is codified in section 2.0 of the *BACB Guidelines for Responsible Conduct* (Table 8.2), which deals with the effectiveness of treatment. From our perspective, arranging "effective" treatment means, first, that the initial selection of an intervention is based on scientific evidence indicating that the intervention is likely to produce the desired effects in any person exposed to it. That is, treatment selection is evidence based. "Effective" also means that the intervention actually produces the desired effects in the person exposed to it, without producing offsetting untoward effects, and that the desired effects are sufficiently large to be of clinical benefit to the client.

Deciding whether or not existing research indicates that a particular intervention is effective depends upon the type of research believed to provide admissible evidence and the findings of such research (Mesibov and Shea 2011). Behavior analysts typically employ small-N, repeated-measures experimental designs and are likely to consider a treatment effective if most individuals exposed to the treatment produce data that are indicative of an effect in the desired direction that is of sufficient magnitude to be clinically significant. They typically analyze data by visual inspection and do not rely heavily on inferential statistics. There are a number of compelling arguments supporting the use of these research methods (e.g., Horner et al. 2005; Poling et al. 1995). Outside of the field of behavior analysis, however, small-N, repeated-measures designs are often viewed with the same derision as case-study designs, and the distinction between the two seems to be poorly understood.

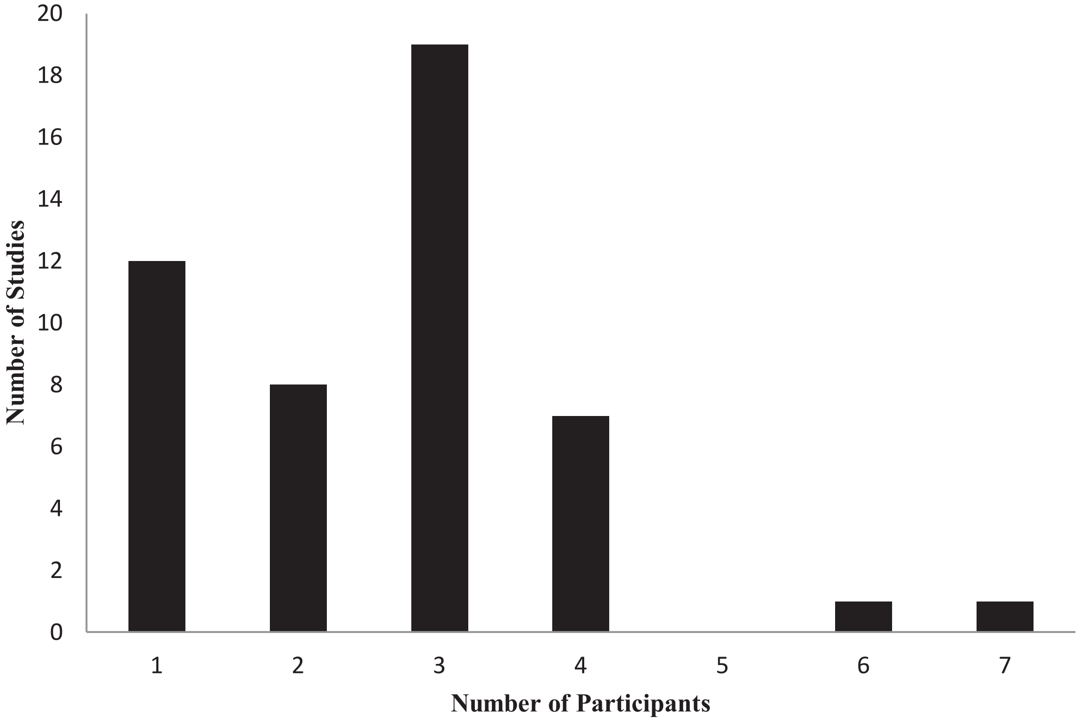

Fig. 8.1 Number of participants in the 48 studies exclusively examining individuals diagnosed with autism spectrum disorders published in the *Journal of Applied Behavior Analysis* from the summer 2010 issue to the spring 2012 issue. No study included more than seven participants

For most scientists, the gold standard for determining the effectiveness of an intervention is the randomized between-groups clinical trial, with statistical data analysis. As Smith (2012) noted in an article published in *The Behavior Analyst,* randomized clinical trials are regarded highly for many good reasons, including the fact that they are useful for performing large-scale evaluations of the efficacy of interventions, a point that is particularly important to funding agencies. He also mentioned that non-behavior analytic interventions are starting to gain approval as early intervention for children with autism because their efficacy is being demonstrated through randomized clinical trials rather than small-N research designs.

In the National Autism Center's (2009) evaluation of interventions for individuals diagnosed with autism, small-N, repeated-measures designs (single-subject designs) with at least 12 participants were included when determining which interventions could be considered to be "established" as effective (this is the best-documented category of interventions). Single-subject designs with at least six participants were considered when deciding which interventions were considered to be "emerging," but designs with fewer than six participants were not included in the evaluation. Figure 8.1 shows the number of participants with autism (or another autism spectrum disorder) studied in each of the 48 articles published in the *Journal of Applied Behavior Analysis* from the summer 2010 issue through the spring 2012 issue that studied only people with such a diagnosis. None of these studies involved 12 or more participants and only two studies (4 % of the total) involved six or more participants. Therefore, regardless of the treatment studied or its effects, none of these studies meet the National Autism Center's (2009) criterion for demonstrating that an intervention is "established" as effective and only two could provide evidence that an intervention is "emerging" with respect to effectiveness.

Children with autism are a vulnerable, protected group and serious ethical issues must be considered when evaluating any proposed study. For example, when randomized clinical trials are conducted, an untreated control group is needed to ascertain the true effectiveness of the early intervention of interest, but withholding treatment from children is difficult to justify ethically, especially when some clearly useful options are already available. Given this consideration, the proper design might compare the intervention of interest to the best possible alternative, perhaps EIBI. This arrangement would provide clinically useful but scientifically incomplete information. Reviews of early interventions commonly lament the paucity of well-controlled studies (e.g., Reichow and Wolery 2009; Rogers and Vismara 2008). That relatively few methodologically sound studies have appeared appears to primarily reflect the formidable ethical and practical challenges faced by researchers rather than a lack of skill or resources.

It is obvious, but worth noting, that nothing prevents researchers and research consumers from establishing criteria for determining the effectiveness of particular interventions based on data from small-N, within-subject experiments. Odom et al. (2003) attempted to develop a methodology for doing so and used that methodology to characterize intervention practices as "well established," "emerging and effective," and "probably efficacious." Based on a review of 37 articles published from 1990 to 2002, they reported that "adult-directed interventions," and "differential reinforcement of desired behavior" were well established and that "peer-mediated interventions," "visual supports," "self-monitoring," and "involving families," were "emerging and effective." These categories differ substantially from and are more narrow than those used in other reviews (e.g., National Autism Center 2009; Rogers and Vismara 2008), the methods used to assign interventions to categories (e.g., as well established vs. emerging and effective) are neither clear nor obviously objective, and the procedures used by Odom et al. have not been widely adopted. At present, it appears that there is no good and accepted method for determining general treatment effectiveness based on the results of within-subject experiments.

Therefore, one must ask: Is it ethical to recommend as effective a treatment that has not been shown to be effective in a large-N, between-groups study? And is one such study sufficient? Or two? There is at present no clear evidential standard for determining when an intervention is and is not effective (Mesibov and Shea 2011) and it appears that the best one can do is to be aware of the evidence regarding the effects of a given intervention, to describe that evidence as accurately as possible to people with a legitimate interest in the child who may be exposed to that intervention (e.g., the child's parents), and to make decisions based on the best evidence available. Regardless of the evidence supporting the general effectiveness of an intervention, it is essential to evaluate the effects of that intervention in the individual child. Only in that way can one ensure that the intervention does no harm and at least some good, which is the crux of an ethical intervention.

Behavior analysts performing research on early interventions for children diagnosed with autism should consider employing randomized clinical trials whenever feasible, especially when single-subject data can be collected simultaneously (see Poling et al. 1995, pp. 103–127). Experimental designs that provide information about an intervention's influence at the group as well as the individual level are a compromise in that some participants are not exposed to the intervention until later in the study, if at all, and independent variables generally cannot be adjusted based on individual outcomes. These are certainly undesirable features of those designs. Nonetheless, failure to conduct randomized clinical trials and appropriate statistical analyses could result in the exclusion of many effective behavior-analytic interventions from lists of empirically validated interventions for children diagnosed with autism. When examining new interventions or when doing applied work, small-N, repeated-measures studies might be the only realistic option, but when there is good evidence that an intervention shows promise, we should take the final step and test the intervention via randomized clinical trial. Additionally, when analyzing treatment options, although proper precautions must be taken, an intervention should not be disregarded just because its validation is based on randomized clinical trials. As Mesibov and Shea (2011) point out:

> [The concept of evidenced-based-practice has] significant financial and legal implications. An unfortunate recent trend is for approaches to claim that they are the 'only' evidence-based or scientifically-proven approach and to encourage parents to demand that public funds be used to support the approach in question. (p. 125)

People who advocate for EIBI do so for good reason, but stating their case too strongly is unwise and may border on unethical.

It is noteworthy that the *BCBA Guidelines* require behavior analysts to recommend "the most effective treatment procedures" and to review and appraise "likely effects of all alternative treatments, including those provided by other disciplines and no intervention." These are tall orders, easily voiced but nearly impossible to follow. In many cases, there are no direct comparisons of alternative intervention. For instance, as Weeden et al. (2010a) point out, both risperidone (Risperdal) and behavior-analytic interventions are used to reduce problem behavior in children with autism and there are published data indicating the value of both.

There are, however, no direct comparisons and the research methods used to evaluate the effects of risperidone and behavior-analytic interventions differ sufficiently to make cross-study comparisons problematic. In addition, a wide variety of behavior-analytic procedures are used to reduce undesired behavior, making it nearly meaningless to compare "risperidone" to "behavior analysis." Finally, as noted previously, the long-term effects of exposure to risperidone are unknown. Even if a behavior analyst is fully knowledgeable with respect to published studies, she or he will be hard pressed to say whether risperidone or a given behavior-analytic procedure is "most effective." Moreover, it is not realistic to expect most practitioners to be conversant with research outside their area of expertise, or to have the skills or time to evaluate this research. If they do not, are they irresponsible or unethical? We think not.

Many interventions for individuals diagnosed with autism originate outside of the field of behavior analysis. As we emphasized previously, non-behavior-analytic interventions should not be dismissed out of hand, and some are of documented value. Nonetheless, many of them have no supporting evidence, have been demonstrated to be ineffective, or have been shown to be harmful. It is not a practitioner's obligation to be aware of all alternative therapeutic interventions and the status of those interventions, but situations can arise in which an individual with whom a practitioner is working might be exposed to questionable or potentially dangerous interventions. If, for example, a practitioner discovers that a child with whom she or he is working will be exposed to chelation therapy, what action, if any, should the practitioner take? Chelation therapy is used appropriately to remove heavy metals, such as lead and mercury, from the body (Klassen 2006), but there is no evidence that lead, mercury, or any other heavy metal causes autism, there is no evidence that chelation therapy benefits children (or adults) with autism, and there is clear evidence that such therapy is dangerous (Weber and Newmark 2007). Therefore, its use to treat children with autism appears to be unethical.

Because chelation therapy is dangerous (and potentially lethal) does a behavior-analytic practitioner have an obligation to inform the guardian of a child with autism who is a candidate for chelation therapy about the status of research on chelation therapy and the potential for harm to the child even if that practitioner has no direct role in the treatment? In our view, he/she probably does. There is a risk, however, of such a practitioner voicing opinions regarding that which she or he has no real expertise, and in so doing venturing onto shaky ground. Standard 1.02 (Competence) of the *BACB Guidelines* (2010) specifies that:

> (a) Behavior analysts provide services, teach, and conduct research only within the boundaries of their competence, based on their education,

> training, supervised experience, or appropriate professional experience.
>
> (b) Behavior analysts provide services, teach, or conduct research in new areas or involving new techniques only after first undertaking appropriate study, training, supervision, and/or consultation from persons who are competent in those areas or techniques.

Most behavior analysts are not trained in psychopharmacology, medicine, or occupational therapy. If that is the case, is it ethical for them to provide information to parents or guardians of children with autism regarding the nature or probable effects of psychotropic medications, chelation therapy, or sensory integration? And how does the ethical obligation for competence prior to service delivery relate to the ethical obligation to review and appraise "likely effects of all alternative treatments, including those provided by other disciplines and no intervention?"

Another significant issue regards how a practitioner should proceed when it appears that a child with autism is a candidate for treatment with an intervention that is apparently harmless but also useless that is, of no benefit to the child. In such cases, it appears to be good practice to inform the child's guardian of the relevant research findings and suggest in a tactful way that the proposed treatment is highly unlikely to be of benefit. In the event that the child's guardian still wants to continue with the intervention, the practitioner could offer to take data to determine whether or not the intervention actually is effective if doing so is tenable, or offer a suggestion as to how others could collect and interpret relevant data.

When dealing with "harmless but ineffective" interventions, such as requiring children to wear weighted vests (for a review see Stephenson and Carter 2008), practitioners, parents, and other individuals concerned with the child's well-being should be made aware that these interventions are often costly and time consuming and may cut into resources that could be allocated to effective therapy. In addition to their opportunity cost, interventions that are not obviously harmful may in fact have unintended negative consequences that are real but difficult to quantify. For example, requiring a child with autism to wear a weighted vest may be socially stigmatizing and negatively affect interactions with other children.

If there are no compelling data indicating whether an intervention is harmful in children with autism, but there is reason to believe that this may be the case, practitioners should proceed cautiously in making recommendations and base those recommendations on whatever evidence is available, being sure to relate the nature of that evidence to others with a legitimate interest in the quality of life of the child in question, such as her or his parents. For example, we have noted that risperidone is FDA approved for the treatment of irritability in children with autism and that there are data indicating that it can be effective for this purpose. As we have also indicated, the drug is known to produce a range of untoward short-term effects, but its long-term effects in children with autism are unclear and the likelihood that a given child will experience adverse reactions cannot be confidently specified *a priori*.

It is noteworthy that the makers of Risperdal (the trade name of risperidone) were recently fined about US$ 1.2 billion by the state of Arkansas for downplaying the negative side-effects of the drug (Muskal 2012, April 11). Although the efficacy of the drug has been validated through clinical trials, this news seems to suggest that many parents and guardians decided to expose the children in their care to Risperdal without full knowledge of its potential to do harm and that the children were harmed by that exposure. Is a behavior analyst working with parents or guardians whose children are, or might soon be, exposed to Risperdal ethically obligated to inform them of the recent developments regarding Risperdal noted above, even though the behavior analysts is not expert with respect to psychopharmacology or law and is not legally empowered to administer the drug?

The Need for Intervention

So far, this chapter has been written under the working assumption that children diagnosed with autism should be exposed to interventions designed to help them behave similarly to their typically developing peers, but this assumption may merit scrutiny. In this section, we examine arguments for and against the implementation of interventions intended to change the behavior of people diagnosed with autism.

Some representatives of autism rights groups argue that autism is an example of "neurodiversity" and that attempting to "normalize" individuals who have been diagnosed with autism is a violation of their rights. Advocates of this perspective see autism as a defining and fundamental aspect of an "autistic" individual and promote the acceptance of autism rather than attempts to "cure" autism, which, they argue, is not a disease or disorder (Harmon 2004). In an extreme example of this perspective, Dawson (2004) decries EIBI as a gross violation of numerous ethical standards and the basic rights of children diagnosed with autism. One of her major gripes with behavior-analytic interventions is that they are intended to change individuals by making them "less autistic," which implies that autism is an undesirable condition. It is abundantly clear that *people with autism* are in no sense undesirable and have precisely the same rights and prerogatives as people without the diagnosis. Moreover, discriminating against such people in any way is unethical and promoting the full acceptance of people with autism, despite their unique characteristics, is highly desirable. Nonetheless, the behavioral characteristics exhibited by children with autism that lead to their diagnosis are less than desirable in that their occurrence limits opportunities for reinforcement in the everyday world and therefore the quality of their present and future lives. Changing these behaviors early in life to the fullest extent possible appears to be in the best interest of the children and in our view arguments against early interventions in general are both few in number and misguided.

In fact, a reasonable argument could be made that it is unethical to withhold early interventions from a child diagnosed with autism. In pursuing this point, Moon (2010) describes a scenario in which a medical doctor identifies clear autistic behavioral characteristics in a young patient and asks the child's parents about the interventions he has received, to which the parents reply that he does not need therapy because his differences are simply an example of neurodiversity and there is nothing wrong with him. The doctor, who works at an autism clinic, feels conflicted about her responsibilities. She is obligated to respect the parents' decisions as caregivers, but she also has a responsibility to help the child develop into a healthy, autonomous individual. Moon suggests that the doctor should refer to the guidelines outlined by Diekema (2004, p. 252) and base her actions on answers to the following questions:

1. By refusing to consent are the parents placing the child at significant risk of serious harm?
2. Is the harm imminent, requiring immediate action to prevent it?
3. Is the intervention that has been refused necessary to prevent the serious harm?
4. Is the intervention that has been refused of proven efficacy, and therefore, likely to prevent the harm?
5. Does the intervention that has been refused by the parents not also place the child at significant risk of serious harm, and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents?
6. Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents?
7. Can the state intervention be generalized to all other similar situations?
8. Would most parents agree that the state intervention was reasonable?

If the answer to all questions save number 6 is "yes" and the answer to Question 6 is "no," then withholding treatment is unethical. Therefore, the doctor in our scenario should respect the parents' decision and take no forceful action against them because the child is not in immediate danger of significant harm.

Although the strategy proposed by Diekema (2004) for evaluating the ethicality of withholding treatment relies on subjective evaluation and is not universally accepted, it does appear to align well with legal opinion. For example, Diekema (2004) recounts a case in which the parents of a child with Burkitt's Lymphoma refused to expose him to chemotherapy, which offered a 40 % chance of survival. The court ruled in favor of the parents' decision because, although the alternative to the treatment was certain death, "[chemotherapy] is extremely risky, toxic, and dangerously life-threatening" (p. 256).

In most cases, children who meet the diagnostic criteria for autism are not in immediate danger of significant harm and, therefore, it is unlikely that courts would require exposure to EIBI or any other early intervention. In cases involving serious self-injurious behavior or other life-threatening behavior, however, the court might rule in favor of forced intervention despite parental objections. In such cases, the intervention must be "proven to be effective," which raises issues concerning the standards of evidence required for demonstrating effectiveness. These issues were discussed previously.

Many autism rights activists agree that people who have been diagnosed with autism should be exposed to education and therapy (e.g., Sinclair 1998), but due to their perception of "autistic" individuals as fundamentally and permanently different from "non-autistic" individuals, they argue that the methods and goals of education for "autistics" should also be fundamentally different from the methods and goals for "non-autistics." Ignoring for a moment the implicit assumption that autism is an all-or-none condition, which appears to be in conflict with data suggesting that "autistic" behavioral characteristics are normally distributed, the meat of the argument could be rephrased as a question: Do learning mechanisms for "autistic" individuals differ significantly from learning mechanisms for "non-autistic" individuals? Some autism rights activists say the answer is "yes" and, like Dawson (2004), contend that EIBI does not take these differences into account. Moreover, they believe that the methods employed in typical EIBI are inappropriately directed at normalization ("in the sense of making children with autism normal," that is, like other children) rather than habilitation of children with autism. In sum, according to this argument, EIBI is suboptimal and misguided. Although part of the foundation for this argument, regarding the nature of autism, appears to be on shaky ground, the accusations are serious and should be addressed.

As discussed in the context of "the right to effective treatment," if one type of treatment is found to be more effective than another type, with few exceptions (e.g., the alternative treatment is also dangerous), the more effective treatment should be pursued. Without evidence for a more effective method of education, criticism of EIBI as suboptimal falls flat. EIBI is founded on principles of learning that transcend race, strain, species, and diagnosis. It is unlikely that a certain subset of the human population is exempt from the orderly influence of the environment on their behavior, and there is much evidence documenting the effectiveness of behavior analytic methods in changing the behavior of children diagnosed with autism. Additionally, unlike many alternative interventions, EIBI is highly individualized in that the strengths and weaknesses of individual children are taken into account throughout the educational process. This personalized approach is particularly important for individuals diagnosed with autism given that their behavior and its controlling variables sometimes differs significantly from that of typically developing individuals.

Although EIBI is individualized, the National Academy of Sciences National Research Council recognized that effective programs have certain general features. For example, they start early in life (by 2–3 years of age), run each weekday year round for at least 25 h a week, have a low (1 or 2 to 1) teacher (or therapist-) to child ratio, utilize structured (rather than unstructured or discovery based) programs, are conducted in quiet and non-distracting environments, emphasize developing communication and social skills, prevent the emergence of challenging behaviors, involve parents, and arrange interactions with typically developing peers (Thompson 2007). If EIBI did not have unifying characteristics, it would be impossible to evaluate its general effectiveness or to disseminate it widely to serve the interests of children with autism.

Concluding Comments

We have introduced a substantial range of issues under the guise of ethics. Whether those issues are, in fact, ethical issues depends solely on one's perspective. All of the issues, however, are relevant to the well-being of children who may be diagnosed with autism and exposed to early interventions intended to deal with the behavioral excesses and deficits that are the basis of the diagnosis. For that reason, they are important issues. Many of them also are complex. "Autism" is a broad, heterogeneous, and murky diagnostic category and the specific needs of children who receive this diagnosis differ substantially. Further research is needed to ascertain the etiology of those needs and the best tactics and strategies to meet them. As Rogers and Vismara (2008) point out:

> It is clear that the field is still very early in the process of of determining (a) what kinds of interventions are most efficacious in early autism, (b) what variables moderate and mediate treatment gains and improved outcomes following intervention, and (c) the degree of both short-term and long-term improvements that can reasonably be expected. (p. 8)

Ethical conduct requires practitioners to do their best to stay abreast of the research literature and consistently endeavor to implement best practices for children with autism. At present, EIBI as initially developed by Lovaas is the sole comprehensive treatment generally recognized as "well established" (Rogers and Vismara 2008) and it is certainly appropriate for behavior analysts to advocate for and consistently utilize it.

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Economics of Autism Spectrum Disorders: An Overview of Treatment and Research Funding

9

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Keywords

Funding · Insurance · Third party payment

Without question, autism research and treatment are big business. Autism impacts multiple aspects of the lives of individuals with autism spectrum disorder (ASD), their families, and the communities in which they live, attend school, and engage socially and vocationally. With no easy cure or preventative measures on the horizon, the field of autism treatment has attracted a plethora of questionable industries, promoting everything from dolphin therapy to fad diets. While researchers around the globe endeavor to determine the etiology of ASD, the reality is that intervention based on the principles of applied behavior analysis (ABA) remains the only evidenced-based treatment for children with ASD. While fidelity and reliability are critical to its effectiveness, bad purveyors of ABA are ubiquitous, triggering government task forces and certificate programs as local, state, and federal governments struggle to regulate a growing multibillion-dollar business.

As the number of children with ASD continues to increase, scientists and pundits debate what percentage of the increase is the result of improved screening and broader diagnostic criteria and what percentage represents an actual uptick in the prevalence of the disorder. Such nuances may be relevant to researchers, nonprofits, and NIH institutes in pursuit of a cure, but for those individuals and families grappling with an ASD diagnosis, the only genuinely relevant issue is treatment. What works? What does it cost? Who will pay for it?

The answer to the first question—what works—seems to be straightforward, with little to no evidence for treatments outside of ABA-based treatment showing the potential to bridge the development gap between children with ASD and their typically developing peers (Fein et al. 2013; Howard et al. 2005; National Autism Center 2009; Remington et al. 2007). While most, if not all, informed and impartial professionals acknowledge the effectiveness of ABA-based behavioral treatment in increasing wanted behaviors and diminishing unwanted behaviors, the challenge of ABA is the intensity and duration that it requires in order to achieve the optimal result. Consequently, the answer to "what does it cost" is that ASD treatment is expensive—minimally

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(US$ 50,000) a year—and, as a result, the answer to the third question—who will pay for it—has produced a complex, multitiered network of responsible parties with schools and governments initially shouldering most of the costs.

Recently, however, the growing numbers of individuals with ASD, along with the utterly unbiased way in which it seems to have disregarded cultural, ethnic, economic, and social barriers, have produced rare consensus among scientists, politicians, races, and cultures that treatment for children with ASD is a moral, societal, and economic imperative. More importantly, perhaps, from an economic standpoint, is the impact of individual lawsuits and state-by-state legislation that have established ABA-based treatment as a medical necessity. As a result, over 30 states have implemented laws for the first time mandating that private insurance carriers pay for ABA-based treatment for children with ASD. While behavioral health treatment is included under "essential health benefits" (EHB) required in small group and individual insurance policies as a result of the federal Affordable Care Act, the states have been given latitude as to how they define each EHB. Currently, just over half of the states include ABA-based autism treatment in their definition of behavioral health treatment.

Autism treatment itself is not nearly as complicated or challenging as the bureaucratic idiosyncrasies that confront the parents and caregivers of children with ASD, their doctors, teachers, and service providers. In the USA, years of insurance industry lobbying, community activism, and eventual mental health parity laws have resulted in a tangled patchwork of laws, regulations, and policies intended to minimize, shift, or share the economic burden associated with autism treatment. Internationally, data regarding the costs associated with autism are more difficult to find but make it clear that, in communities that are not economically impacted by autism, individuals with ASD are without adequate services, treatment, and support.

Cost of Treatments for Autism Spectrum Disorders

Research has shown that early intervention is necessary for individuals who have ASD, and the leading treatment for ASD is early intensive behavior therapy based on the principles of ABA. Numerous studies have provided empirical evidence for the effectiveness of this approach for children with ASD, documenting substantial gains in functioning and the potential loss of the diagnosis altogether (Boyd and Corley 2001; Birnbrauer and Leach 1993; Cohen et al. 2006; Fein et al. 2013; Howard et al. 2005; Lovaas 1987; McEachin et al. 1993; Sallows and Graupner 2005; Smith et al. 2000).

With an early diagnosis, the optimal intensity of ABA-based therapy may be as much as 35–40 h per week, which is estimated to cost between US$ 40,000 and US$ 60,000 when provided in the home (Chasson et al. 2007), with some programs costing as much as US$ 100,000 per year (Zane et al. 2009). Typically, a child who begins an ABA program at the age of three will require at least 3–5 years of treatment (Jacobson et al. 1998), costing a minimum of US$ 120,000 before the child reaches middle school, and children with ASD often continue ABA treatment programs well into adolescence. These estimates are based on a 35–40-h-per-week program, and ultimately, the annual cost of an ABA treatment program will depend on multiple factors, including the agency providing the services, where the services are provided (home, center, school, or hospital), the experience of the individuals providing treatment, and the number of hours provided per week of 1:1 therapy.

According to a report of special education spending by the Center for Special Education Finance for 1999–2000, special education services cost an average of US$ 12,639 per student. When compared to students receiving general education services, it was estimated that a special education student's expenditures were 2.8 times more per year (Center for Special Education Finance 2004). More recently, in a paper on the cost comparison of special education and behavioral intervention services, Chasson et al. (2007) reported the annual cost of special education services in Texas to be approximately US$ 11,000 per child. The cost of behaviorally based educational services is likely to be much higher in school districts that provide ABA-based interventions, such as discrete trial training (DTT), on a 1:1 or 1:2 ratio within the classroom and when additional staff trainings are required.

Although occupational therapy (OT) and speech therapy are typically provided by a school district and included in the annual cost of special education services, individuals who choose to pay privately for these services face substantial costs. The average cost of OT services can range from US$ 50 to US$ 400 per hour, depending on the individual needs of each client, and speech therapy typically costs from US$ 100 to US$ 250 per hour (Treatment 2010). Chasson and colleagues' (2007) comparison of the cost of 18 years of special education services to the costs associated with early intensive ABA indicated that, in the state of Texas, 3 years of ABA could result in a savings of US$ 208,500 per child. Although the initial cost of 3 years of ABA is greater than the first 3 years of special education services, the early investment in ABA substantially reduces costs over the next 15 years. Lifetime cost-benefit analyses of early intensive behavior therapy will be discussed later in the chapter.

Cost of Fad Treatments

A fad treatment can be described as a treatment with little scientific support that becomes popular through anecdotal reports of effectiveness, mass media, and/or endorsement by celebrities (Zane et al. 2009). The availability of information on fad treatments in the media and on the Internet can result in a high cost to society. As parents proactively search for information and potential help for their children with ASD, the accessibility of unproven treatments accompanied by passionate, albeit undocumented, testimonials may divert parents away from scientifically proven treatments, such as ABA. Consequently, the cost of fad treatments may be twofold, with parents bearing the financial cost of the treatment itself but society bearing the broader financial cost associated with an individual who fails to achieve independence because parents provided the child with a fad treatment rather than a scientifically valid treatment.

Some examples of fad treatments include special diets (e.g., gluten-free and casein-free diet), sensory-based interventions (e.g., sensory integration therapy (SIT) and auditory integration therapy), biomedical interventions (e.g., vitamin injections, hyperbaric oxygen therapy (HBOT), and chelation therapy), and nonmedical interventions (e.g., dolphin therapy, equine therapy, and music therapy). Studies that have been conducted on these treatments show minimal results (Chez et al. 2000; Devlin et al. 2010; Granpeesheh et al. 2010; Jepson et al. 2011; Mudford et al. 2000). These treatments are typically very costly, ranging from US$ 60 for a 2-week supply of secretin injections (Treatment 2010) to as much as US$ 20,000 for animal-assisted therapy (Autism Service Dogs of America 2010). Families often combine different fad treatments and continue these treatments even if results are not observed. If these interventions are implemented in addition to an ABA-based program, progress may be attributed to the fad treatment, which in turn results in false anecdotal reports contributing to more people using fad treatments instead of empirically validated interventions.

Zane and colleagues (2009) reported the costs of two well-known and widely used fad treatments, i.e., SIT and Relationship Development Intervention (RDI). Annual costs are estimated at US$ 16,500 for SIT and US$ 10,000 for RDI. Research on these two treatments has shown varied results, with some studies suggesting moderate improvement and others suggesting no change. When comparing the effectiveness of these treatments to the empirical support and cost-benefit analyses supporting early intensive ABA, the widespread and continual use of fad treatments like these is concerning, especially considering the immense costs and the increased likelihood that a child with ASD will not receive the scientifically proven treatment that offers the greatest opportunity for improvement.

Focusing on Established Treatments

Various interventions have been developed as treatments for children with ASD. Some of these interventions have foundations in empirically supported research, and others have not been extensively evaluated to determine their efficacy. These interventions include the Son-Rise Program, Social Communication/Emotional Regulation/Transactional Support (SCRETS), Early Start Denver Model, Floortime, and Training and Education of Autistic and Related Communication Handicapped Children (TEACCH), among others. The costs of these treatments vary widely depending on the program length, intensity, and the type of professional implementing the intervention. For example, Floortime sessions at Rush University Medical Center cost US$ 125–US$ 150 per 1-h session (Rush University Medical Center n.d.), and the Son-Rise Program provides a start-up course that costs US$ 2,200 for a 5-day group training program (Autism Treatment Center of America 2012).

While these interventions have some research showing improvements, they generally do not have empirical support to the same extent as early intensive ABA-based interventions. According to the National Standards Project, a report developed by the National Autism Center that categorizes interventions aimed at individuals with autism based on the amount of empirical support, the intervention strategies incorporated into most early intensive ABA programs are considered established treatments (National Autism Center 2009). Moving forward, with limited resources to cover treatment costs for a growing number of individuals with ASD, it is imperative that local, state, and federal policies and funding sanction those interventions with substantial empirical support, specifically early intensive ABA-based interventions.

Treatment Funding

The heterogeneity that characterizes ASD has hindered the development of adequate systems of care for individuals with ASD, who require a broad array of individualized services, often throughout their lifespan. The public policies, guidelines, and legislation intended to address the health care needs of individuals with ASD have, instead, created a tangled patchwork of laws and policies that morphs from state to state, confusing even the experts who are trained to decipher such anomalies. Parents and caregivers routinely find themselves appealing denials of service and citing legislation to the very individuals charged with enacting it long before such legislation manifests itself as tangible services for individuals with ASD.

The Centers for Medicare & Medicaid Services (CMS) ASD Services Project described what it called the “siloed fragmentation of state health and human services programs” in its *Report on State Services to Individuals with Autism Spectrum Disorders (ASD)*:

> While screening and diagnostic services may be funded by Title XIX of the Social Security Act (Act) under state Medicaid programs and delivered by pediatric or primary medical care practitioners, for example, prevention and early intervention services may be funded by Title V/Maternal and Child Health under the aegis of departments of public health. Other early treatment services may involve funds and programs from departments of mental health and/or developmental disabilities services and by departments of education implementing the Individuals with Disabilities Education Act (IDEA) mandates and child welfare agency services.

This lack of a single cohesive resource for services has caused widespread disparity in treatment funding, as well as funding for additional services, which is often disproportionately distributed to those who have the time, education, and resources to pursue it. Furthermore, recently enacted state mandates requiring private insurance carriers to provide ABA for children with ASD, as well as the Patient Protection and Affordable Care Act (PPACA)’s “essential health benefits,” which took effect in 2014, may potentially create enormous disparity between the treatment received by a privately insured child with ASD versus the treatment provided to a child receiving publicly funded health care benefits.

Since the 1990s, insurance companies and federal and state agencies have funded treatment for children with autism to address health care issues that are commonly associated with developmental disabilities in general, including speech therapy, OT, prescriptions, and doctor visits. Early intensive behavioral intervention (EIBI) using ABA, however, has consistently been excluded from most health care benefits. Private insurers and states often justify its exclusion by citing a lack of evidence to support its effectiveness, by claiming that behavioral therapy is experimental, and/or by characterizing ABA as educational and, therefore, not a medical treatment (Blue Cross Blue Shield Technology Evaluation Center 2009). Often, lengthy litigation becomes the sole recourse for families whose insurance carriers have denied medically necessary behavioral health care treatment for their children with ASD.

Christopher E. Angelo, Esq., a litigation attorney and advocate for the rights of the developmentally disabled, educates parents throughout the USA in "perfecting medical insurance coverage" (Angelo 2012). In many instances, parents have compelled private insurance companies to pay for costly intensive behavioral and other treatments using Angelo's free legal pamphlet, *The Law of HMO/PPO Special Needs State Mandates,* based in part on legal precedent he established in *Broughton v. Cigna Healthcare Plans* (1999). Angelo successfully asserted for his own son that the consecutive hours and structured environment which are so fundamental to intensive behavioral intervention more closely resemble the confinement associated with "hospitalization" for which benefits are unlimited. Angelo's pioneering efforts to compel insurance companies to pay for intensive behavioral therapy within the context of "partial hospitalization" are likely somewhat responsible for the recent willingness of some insurance companies to cover comparatively less costly outpatient behavioral health treatments.

Even as some states and insurance companies have begun to recognize the medical necessity of ABA for children with ASD, stories of arbitrary denial of ABA treatment are plentiful and continue to give rise to groundbreaking legislation. As recently as March 2012, the US District Court (Southern District) in Florida issued an Order enjoining Florida's Medicaid program from enforcing a state rule that excluded ABA treatment for minors with autism and compelling the State of Florida to "provide, fund, and authorize Applied Behavioral Analysis treatment to … all Medicaid eligible persons under the age of 21 in Florida who have been diagnosed with autism or Autism Spectrum Disorder" (K.G. v Dudek 2012).

The judge in *K.G. v. Dudek* ruled that "… paying for the cost of ABA for autistic children will ultimately save the public funds …" because many children with ASD who do not receive ABA become adults who are totally dependent on community and government services (K.G. v Dudek 2012). While a treatment plan with 30–35 h of ABA treatment per week costs as much as US$ 50,000 a year, research published by Harvard University's School of Public Health demonstrates that 3–5 years of intensive behavioral intervention represents a savings to society of nearly US$ 3,000,000 per capita when that treatment enables a child to grow into an independent, contributing member of the society (Ganz 2007). Indeed, Ganz (2007) calculated direct, indirect, medical, nonmedical, and loss of earnings potential across the lifespan to conclude that, on average, an individual with ASD can potentially cost US$ 3.2 million over his or her lifetime. Moreover, in a joint study between University of Pennsylvania and the London School of Economics and Political Science, David Mandell, Sc.D., and Martin RJ Knapp, Ph.D., estimate the annual economic cost of autism in the USA at US$ 126 billion per year (Knapp et al. 2012).

Since the 1970s, as states have identified the cost-effectiveness of policies that keep children with ASD at home with their families and out of institutions, comprehensive community-based care systems have played integral roles in providing and/or coordinating services for individuals with ASD. Individuals with ASD and their families rely on these systems in conjunction with public schools to obtain the services they require. Until recently, when some states began mandating private insurers to provide coverage for ABA, a greater number of children with ASD (46 %) utilized public insurance to obtain the health services they required when compared to children with other disabilities (Liptak et al. 2006).

Funding Through State Public Educational Systems

Given that ABA-based EIBI is the single scientifically established treatment for ASD, informed parents pursue it ardently (National Autism Center 2009). Because most insurance plans have not traditionally covered ABA, parents have relied on the Individuals with Disabilities Education Act (IDEA) to try to compel public schools to provide or reimburse them for the behavior therapy they seek for their children with ASD. Since a child with ASD often experiences educational delays, public schools have a legal obligation, mandated by IDEA, to provide services in an effort to remediate those delays. In fact, Liptak and colleagues (2006) found that 98 % of children with ASD require a "special school program."

Individuals with Disabilities Education Act (IDEA) IDEA was enacted in 2004 and replaced the Education for All Handicapped Children Act of 1975 (Public Law 94–142). Prior to the enactment of that law in 1975, children with disabilities were excluded from the public school system altogether. IDEA's main purpose is "to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living" (IDEA 2004). This mandate to provide children with disabilities with "a free appropriate public education" (FAPE) bestows rights on children with disabilities to demand the tools, support, oversight, and personnel required for them to access a "free appropriate public education."

IDEA is commonly summarized as enumerating six principles that form the framework for special education services for students with disabilities:

- Free Appropriate Public Education (FAPE)
- Appropriate Evaluation
- Individualized Education Program (IEP)
- Least Restrictive Environment
- Parent and Student Participation in Decision Making
- Procedural Safeguards

Free Appropriate Public Education (FAPE) Free appropriate public education (FAPE) is firmly established as a right of children with disabilities. What constitutes "appropriate public education," however, is not explicitly defined in IDEA. Since the education that a child with disabilities receives needs to address his or her specific and individual educational needs, that which is "appropriate" for one student may not be "appropriate" for another. Consequently, FAPE is defined on an individual basis, one child at a time. In addition to specifying an appropriate placement for the child in the public school setting, the school must identify and provide the supplementary aids and services in order for the child to succeed in the given educational setting. Parents of children with ASD have successfully used the standard of FAPE to compel public schools to provide ABA to their children, as well as one-on-one aids and the technology that facilitates their child's public education. Public school districts, overwhelmed by the financial cost of ensuring FAPE for increasing numbers of children with ASD while facing diminishing education budgets, have increasingly turned to state and federally funded health care to share the cost.

Medicaid Waivers

Medicaid is jointly funded by the state and federal governments but administered individually by each state. States are given broad discretion to design eligibility and benefits based on the perceived needs of the state. Most Medicaid plans do not cover ABA, but children with ASD can be eligible for ABA services through Medicaid waivers even if they would not otherwise be eligible for Medicaid (Wang and Leslie 2010). Medicaid home and community-based services (HCBS) waiver programs, informally called Medicaid waivers, are authorized under Section 1915(c) of the Social Security Act in an effort to create "feasible alternatives" to "inpatient hospital services" (Social Security Act 1935). State Medicaid waiver programs often cover ABA, although eligibility criteria for children with ASD and requirements for providers of ABA therapy vary from state to state (Spigel 2007).

When accessible, Medicaid waivers have been an important resource for children with ASD, providing behavioral health services that might otherwise not be available (Center for Medicare and Medicaid Services 2011). The cost, however, to Medicaid of providing services to children with ASD is high and growing. In a study documenting trends in Medicaid expenditures associated with children with ASD, Wang and Leslie (2010) noted that costs increased by 32.8% from 2000 to 2003, totaling US$ 1,686,938 per 10,000 children with ASD.

Until October, 2010, waivers were unlike other Medicaid coverage because states could limit the number of individuals served within a waiver program, whereas standard Medicaid benefits can only be limited by eligibility requirements established by the state, not limited to a random number imposed by the state in an effort to limit costs. Many states currently offer autism-specific Medicaid waivers, although nearly every state participates in Medicaid waivers for developmental disabilities, which typically include autism. ABA-based intervention services may be covered by Medicaid waivers in states that have a waiver program for developmental disabilities, not just in states with waivers for autism (Wang and Leslie 2010). Each state has broad discretion in designing its Medicaid waivers program in order to ensure that it addresses the specific needs of its population. The availability of Medicaid waivers for ABA and the amount of coverage provided once a Medicaid beneficiary receives a waiver vary from state to state and are most affected by individual state budget constraints and state flexibility regarding eligibility requirements.

Medicaid Waiting Lists and the Patient Protection and Affordable Care Act (PPACA)

Often, the limited nature of state Medicaid waiver programs results in long waiting lists for services. A recently enacted provision of the PPACA, which adds Section 1915(i) to the Social Security Act, specifically eliminates the state option to create HCBS waiting lists rather than serve all eligible individuals, although states have been slow to comply with this amendment. In a clarification letter sent to state Medicaid directors in August, 2010, the Center for Medicaid asserted that "…States may no longer establish a wait list for receipt of State plan HCBS" (Center for Medicare & Medicaid Services, personal communication, August 6, 2010). Despite this directive, some states continue to have waiver programs in place that severely limit the number of individuals served. For example, Colorado continues to limit its Medicaid waiver program for autism to 75 children with ASD.

Higher Functioning Children with ASD and Medicaid Waivers Until recently, Section 1915(c) of the Social Security Act authorized the Medicaid HCBS waiver program, allowing states to provide home and community-based services to Medicaid recipients *only* in those instances when such services provided support necessary to enable an individual to avoid or end institutionalization. Because the waivers were authorized in an effort to avoid institutionalizing a Medicaid beneficiary, higher functioning children with ASD were typically ineligible for ABA through the Medicaid waivers. With the passage of the Deficit Reduction Act (DRA) in 2005, which took effect on October 1, 2010, Section 6044 was added to the Social Security Act which eliminated the requirement that beneficiaries meet an "institutional level of care," meaning that HCBS benefits are now available to individuals even if they would *not* be institutionalized without such benefits.

Shifting the Cost Burden

As states have begun to understand the short and long-term costs associated with the increasing numbers of children with ASD, they are also gaining awareness that the brunt of the economic burden has been borne by the state, whether through its public educational system or via Medicaid waivers. In response, many states have passed legislation mandating insurance companies to provide specific services to children with ASD, including ABA. Since 2007, 550 bills have been introduced in 47 states, Washington, D.C., and Puerto Rico. The only states with no autism-related legislation are Idaho, South Dakota, and Wyoming (National Conference of State Legislatures 2012). To date, 33 states have mandated such insurance coverage, though annual and lifetime caps and the ages when the children are covered vary widely. For example, Arizona's law mandates that insurance companies provide up to US$ 50,000 in coverage annually for autism-related behavioral therapy, including ABA, until a child is 9 years old and then US$ 25,000 a year until a child is 16, with no lifetime cap on these services. On the other hand, Maine's law only mandates coverage of ABA until a child is 6 years old up to a maximum of US$ 36,000 per year.

Federal Mental Health Parity Act

Interestingly, the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (Federal Mental Health Parity Act) requires that group health plans covering 50 employees or more offer mental health coverage at the same level as their coverage for other medical benefits. Given that federal law overrides state law when the state law contradicts the federal law, the annual limits on ABA coverage embedded in many of the state laws seem to violate the Federal Mental Health Parity Act.

As insurance companies, school districts, and local, state, and federal governments begin to grasp the true cost of providing services to children with ASD, each entity is hoping that the other entities shoulder a greater portion of the economic burden. One reason that coverage for autism services varies so widely is that the determination of the extent to which services should be provided and by whom can be different, depending on the school district, insurance company, and state. The most important variable in this equation has been, by far, the steadfastness of parents determined to get help for their children with ASD. In many instances, parents have to educate themselves about the rights of their children to receive services in order to acquire those services from their children's schools, health care providers, and local government agencies.

Some early exceptions to the lack of insurance coverage of ABA are noteworthy. Many Silicon Valley companies, including Google, Yahoo, AOL, and Adobe Systems, responded to employee pleas and became among the first to include ABA in their group insurance coverage, and the US Department of Defense began providing coverage for intensive behavioral interventions for family members of active duty service members and their families in 2002 (TRICARE Operations Manual 2002).

Insurance

Insurance coverage for autism-related health care varies from state to state and even from month to month. While the PPACA enacted in 2010 makes it clear that new insurance plans must include coverage for autism screening and assessments at no cost to the insured, the word "autism" is never explicitly mentioned in the lengthy document, despite valiant efforts of nonprofit organizations such as Autism Speaks and like Autism Research Group. Instead, the PPACA delineates ten "essential health benefits" which must be included in all private insurance plans by January, 2014, and then mandates each state to develop a standard health insurance plan that includes, at minimum, those ten essential benefits. Section 1302(b)(1) lists the essential benefits, and Section 1302(b)(1) (E) potentially describes coverage of ABA-based treatment, stating as an essential benefit, "Mental health and substance use disorder services, including behavioral health treatment" (Affordable Care Act 2010). Despite this language, however, the secretary of Health and Human Services, Kathleen Sibelius, allowed each state to define the essential health benefits, and nearly half of the states have excluded ABA-based treatment for autism.

Research

Autism research is primarily funded by three sources: (1) federal government grants and contracts awarded by federal agencies, such as the

National Institutes of Health (NIH), Department of Defense (DoD), and Department of Education (Ed); (2) nonprofit organizations, such as Autism Research Group, Autism Speaks, and Simons Foundation; and (3) private corporations, such as the Center for Autism and Related Disorders. The annual combined investment in autism research of these three groups totaled approximately US$ 314 million in 2009 and addresses multiple aspects of autism spectrum disorders, including genetic and phenotypic studies, treatment research to identify and validate effective treatment, product development to enhance the lives of people with ASD and their families, and more.

Federally Funded Research

Combating Autism Reauthorization Act (CARA) In September, 2011, a polarized US Congress, struggling under the weight of substantial economic woes, passed The Combating Autism Reauthorization Act (CARA), which allocates funding for federally funded autism research. Such bipartisan support demonstrates the universally accepted reality that autism research warrants significant funding. The CARA of 2011 allocated US$ 693 million through 2014 to fund autism research undertaken or supported by Health Resources and Services Administration (HRSA), Centers for Medicare & Medicaid Services (CMS), the Centers for Disease Control and Prevention (CDC), and the NIH.

In the USA, over US$ 300,000,000 was invested in autism research in 2009, the latest year for which data are available. That amount represents a substantial increase in funding over the previous year, when US$ 222 million was invested in autism research. While funding by nongovernmental sources remained about the same at US$ 77 million, federal funding for autism research benefited from a one-time infusion of additional dollars as a result of the American Recovery and Reinvestment Act of 2009 (ARRA).

ARRA was enacted in response to the global economic contraction of 2008 and added a total of US$ 10.4 billion to the NIH budgets for 2009 and 2010, US$ 8.97 billion of which was awarded to research grants. Of that US$ 8.97 billion, nearly US$ 64 million was allocated to support new or expand existing autism research. Without the ARRA funding, federally funded research dollars are expected to decrease slightly, along with all other federal grant programs, which have seen their budgets reduced by 0.189 % across the board. Overall, though, federal funding for autism research has nearly tripled in the last decade, given that, in 2001, it totaled just US$ 56 million, the equivalent today of US$ 68 million when adjusted for inflation (http://www.coinnews.net/tools/cpi-inflation-calculator/). According to the *2009 Autism Spectrum Disorders Research Portfolio Analysis Report* produced by the Interagency Autism Coordinating Committee (IACC), federal sources accounted for 76 % of autism research dollars in 2009 while private foundations, nonprofit organizations, and for-profit businesses contributed the remaining 24 %. In 2011, without ARRA funding, federal sources represented approximately two-thirds of autism research dollars, with private foundations, nonprofit organizations, and for-profit businesses contributing the other third.

Allocation of Federal Funding The IACC was established in 2006 to comply with the Combating Autism Act of 2006 which states its purpose as "to amend the Public Health Service Act to combat autism through research, screening, intervention, and education." Section 2 of the Act goes on to say, "The Director of NIH…shall, subject to the availability of appropriations, expand, intensify, and coordinate the activities of the National Institutes of Health with respect to research on autism spectrum disorder … . Such research shall investigate the cause (including possible environmental causes), diagnosis or rule out, early detection, prevention, services, supports, intervention, and treatment of autism spectrum disorder."

IACC is chaired by the director of the National Institute of Mental Health and comprises representatives of five NIH institutes, other interested governmental agencies, at least one individual with autism, and other relevant stakeholders who work together to identify the concerns, needs, and developments affecting the autism community. As a result of the Combating Autism Act, allocation of federal funding for autism research is guided by IACC's annual strategic plan which complies with the Act's stated goals and identifies funding priorities by asking seven questions:

1. When should I be concerned?
2. How can I understand what is happening?
3. What caused this to happen and can it be prevented?
4. Which treatments and interventions will help?
5. Where can I turn for services?
6. What does the future hold, particularly for adults?
7. What other infrastructure and surveillance needs must be met?

IACC's portfolio summaries acknowledge that funding allocated to answer some of these questions has been far greater than funding for other questions. For example, over half of autism research in 2009 addressed Questions 2 and 3 while less than 4% addressed Questions 5 and 6 combined. The IACC portfolio acknowledges that "services and lifespan issues" have received the least amount of funding. Some advocates for individuals with ASD object to this disparity and actively seek a greater balance between funding to identify the cause(s) of ASD and funding to identify effective treatments and services for individuals with ASD. Nonprofit organizations whose research focuses on identifying, validating, and refining effective treatment (Questions 4 and 5), such as Autism Research Group, are conscious of the gap in funding that has arisen as researchers focus on identifying the cause(s) and potential prevention of ASD, and they are committed to restoring a balance between the long-term goals of etiologic research and the current needs of society to identify, develop, and disseminate the most effective treatment for individuals whose numbers continue to grow.

While NIH controls the majority of the federal dollars allocated for autism research, just under US$ 43 million was invested by other federal agencies in 2009, including the Centers for Disease Control (CDC), the Department of Defense (DoD), the Health Resource and Services Administration (HRSA), and the Department of Education (Ed). These non-NIH agencies funded 62 projects in the area of autism research while NIH funded 517 projects.

Cost to Families and Society as a Whole

The financial cost of autism to families varies widely, depending on the severity of the ASD, the state or country of residence of the individual, the extent of comorbid diagnoses, the age of the individual, and whether the individual lives in a private residence, institution, or alternate residential placement, such as a group home. These variables make it difficult to determine the nonmedical costs associated with ASD, although many studies have attempted to quantify the medical costs. Kogan and colleagues (2008) noted that families with children with ASD who had special health care needs more often reported financial problems as a result of an increased need for medical care combined with decreased opportunities for parents to work as a consequence of the child's needs.

Dr. Michael Ganz, of Harvard's School of Public Health, estimates the lifetime total cost of an individual with autism in the USA to be US$ 3.2 million (Ganz 2006, 2007). Ganz produced perhaps the most comprehensive estimate, identifying direct and indirect costs associated with autism, including loss of productivity of the parent and of the individual with autism. Adjusted for inflation, the 2006 figure of US$ 3.2 million increases to nearly US$ 3.7 million in 2013.

Economic Effects of Autism Outside of the USA

Once a year, on World Autism Awareness Day, the World Health Organization (WHO) issues a brief statement urging nations to do more for individuals with autism and their families. WHO describes itself as "… the directing and coordinating authority for health within the United Nations system. It is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries and monitoring and assessing health trends." (World Health Organization 2012). Its role beyond the annual statement is not apparent. Consequently, with the exception of the UK and many European countries, data and anecdotal evidence regarding the economic costs associated with ASD and how those costs are funded are inconsistent and often unreliable or nonexistent. Even in more developed countries, the cost of treatment funding is greatly influenced by place of residence; that is, when treatment costs are low in a particular geographic area, individuals with ASD likely do not have access to adequate treatment (Knapp et al. 2009).

UK In the UK, where ABA-based treatment is accepted as the standard of care for children with ASD, 95 % of the cost of services associated with autism is funded by the government, with the other 5 % funded by the families (Knapp et al. 2009). Data on the cost of treatment for children with ASD in the UK are separated into two sets: children with ASD with intellectual disability (commonly defined as having an IQ below 70) and children with ASD with no intellectual disability. Martin Knapp, Ph.D., of the London School of Economics, and David Mandell, Sc.D., of the University of Pennsylvania, assert that their recent study estimates the cost of autism to the UK to be US$ 54 billion annually. Prior to Knapp's 2012 study with David Mandell at University of Pennsylvania, Knapp and colleagues (2009) estimated that lifetime costs for an individual with ASD and intellectual disability are 50 % higher than the costs for an individual with ASD and no intellectual disability.

When addressing only educational costs, the disparity is even higher, with annual educational costs for children without an intellectual disability estimated at US$ 19,580 and educational costs for children with an intellectual disability estimated at US$ 45,816 (Knapp et al. 2009). Knapp and colleagues (2009) estimated "other health and social care" for children with ASD to be considerably lower for children with no intellectual disability and as high as US$ 11,064 annually for children with ASD and an intellectual disability between the ages of 4 and 11, a number that drops substantially to US$ 641 annually in the 12–17 age group.

Underdeveloped Countries Sporadically, ABA-based treatment is beginning to take root in non-Western countries, such as India, Jordan, and South Africa. Access to treatment is extremely limited, and most information regarding treatment accessibility and its costs is anecdotal, derived from companies with a global reach, such as the Center for Autism and Related Disorders, which provides limited treatment services in remote international locales.

In countries with little or no services for individuals with autism, such as Egypt and China, studies document negligible costs associated with autism treatment (Xiong et al. 2011; Mendoza 2010). Families in Egypt shoulder 95 % of the economic burden associated with raising a child with autism (Mendoza 2010). Xiong and colleagues (2011) calculated the "annual family financial burden" of caring for a child with autism in China at US$ 3,075 per year. Clark and Zhou (2005) assert that few medical providers in China are trained to diagnose and treat ASD, and very limited treatment programs are available, found predominantly in hospitals serving larger cities and a few private schools.

The lack of access to reliable international data and the likelihood that millions of children with ASD receive no treatment whatsoever underscore the fact that, where the economic impact of raising a child with autism is less than US$ 50,000 per capita, individuals with ASD are likely not receiving adequate services.

Conclusion

As the prevalence of ASD continues to grow, the economic toll on individuals, families, and society as a whole is unquestionable. In the USA, the lifetime cost associated with one individual with ASD is estimated to be approximately US$ 3.2 million (Ganz 2006).

At present, ABA is the only scientifically supported treatment for ASD; however, at optimal intensity, this treatment is costly. Although the initial cost of ABA is high, ranging from US$ 40,000 to US$ 100,000 a year, research has demonstrated that ABA is cost-effective, with potential savings in excess of US$ 200,000 for each child who receives 3 years of early and intensive ABA treatment (Chasson et al. 2007). Moreover, the cost to society of not providing ABA to individuals with autism is much greater than the cost of the treatment itself, especially when factoring in the lost productivity of the individuals with ASD and the family members who care for them.

Other services associated with ASD also require large financial outlays, given the growing prevalence of this population. For example, special education services in schools are more than twice as costly per year as general education programs. The cost is even greater in schools that provide ABA-based interventions for students with ASD (Center for Special Education Finance 2004). Fad treatments (i.e., treatments with little scientific support that attain popularity through anecdotal reports of effectiveness, media, or support from celebrities) are not just costly for families; fad treatments with no empirical support extract a toll on society, as well, if the child receiving these treatments fails to achieve independence that might otherwise have been achieved with evidence-based treatment.

The economic burden of autism treatment funding in the USA is shared in varying degrees between state and federal governments, public education, private insurance carriers, and the families themselves. Laws and policies regarding funding for autism treatment are becoming more common, although they differ from state to state. This lack of standardization creates a complex bureaucracy that challenges policymakers, families, insurance carriers, educational institutions, and health care providers in equal measure. For this reason, whether a child with ASD has sufficient funding for treatment often depends on the determination and persistence of that child's family.

Federal laws and funding increase access to treatment and educational options. The IDEA ensures that children with disabilities have access to a "free appropriate public education" (FAPE), and parents and advocates use FAPE to acquire ABA-based intervention for children with ASD when they are in school. Additionally, a child with ASD can be eligible for treatment through Medicaid waivers. Waitlists for Medicaid waivers have been an ongoing concern in states that limit enrollment. Although the Affordable Care Act eliminated waitlist systems, states have been slow to comply, and individuals who are eligible for services encounter multiple challenges when trying to secure them.

As state governments and departments of education have grown cognizant of the cost of ASD treatment, legislation has been crafted to shift the economic burden from the taxpayers to private insurance carriers. Many states have passed legislation mandating private insurance policies to include coverage for ABA-based autism interventions. The annual and lifetime caps, as well as the ages of the children who are covered, vary widely from state to state. However, the Federal Mental Health Parity Act makes those caps a violation of federal law. In fact, the Center for Autism and Related Disorders has successfully removed limits in 12 states on the basis that they violate the Federal Mental Health Parity Act.

Outside of the USA, data addressing the economics of autism are scarce; however, the trend appears to be that adequate treatment is expensive and elusive. In the UK, where ABA is accepted as the standard of care, ASD services are 95 % funded by the government and 5 % by families of children with ASD (Knapp et al. 2009). In underdeveloped countries, access to treatment is limited, there are few clinicians trained to diagnose and treat autism, and the cost of treatment typically falls solely on the families of children with ASD.

In addition to funding services for ASD, millions of dollars are invested in autism research each year. An estimated US$ 314 million was invested in autism research in the USA in 2009, and over US$ 400 million was invested in 2010. A majority of research funding comes from the federal government through the National Institutes for Health, the Department of Defense, and the Department of Education, with nonprofit organizations and private corporations, such as the Center for Autism and Related Disorders, contributing about 18 % of the research funding. The majority of the autism research studies that are funded address causes, prevention, and trends in ASD. The autism community has called for greater investment in services and lifespan issues to address the challenges that individuals with ASD are actively facing each day.

Looking forward, efforts should be made to increase awareness of evidence-based treatment to minimize the potential for individuals with ASD and their families to waste time and resources on ineffective treatment. Additionally, culturally and linguistically appropriate services should be integrated into autism awareness efforts and screening to ensure that cultural and language differences do not become barriers to diagnosis and treatment. Finally, the Affordable Care Act empowers the secretary of Health and Human Services to define the essential health benefits, and this opportunity to include ABA in the essential health benefits should not be forfeited. In lieu of federal clarification, states without autism mandates should move forward to enact mandates to increase access to treatment and to minimize the cost of ASD to their communities in the future.

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Designing Curriculum Programs for Children with Autism

10

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Keywords
Assessment · Curriculum · Treatment planning

Over the last 20 years, early intensive behavioral intervention (EIBI) has become widely recognized as being the most scientifically supported treatment for children with autism spectrum disorders (ASD). Multiple individual studies have been published demonstrating its effectiveness in improving intellectual, communicative, and adaptive functioning in this population (e.g., Cohen et al. 2006; Eikeseth et al. 2007; Howard et al. 2005; Remington et al. 2007). Additionally, both reviews and meta-analyses have confirmed these positive outcomes (e.g., Eldevik et al. 2009; Peters-Scheffer et al. 2011; Reichow and Wolery 2009; Rogers and Vismara 2008). Given this scientific support, EIBI is now endorsed as an effective intervention for children with ASD by several independent bodies, including: the New York State Department of Health (New York State Department of Health, Early Intervention Program 1999), U.S. Surgeon General (U.S. Department of Health and Human Services 1999), National Academy of Sciences (National Research Council 2001), and American Academy of Pediatrics (Myers and Plauché Johnson 2007).

EIBI programs commonly involve providing 1:1 behavioral intervention to remediate skill deficits and reduce challenging behavior. Ideally, intervention begins as early as possible (usually before the age of 5; Love et al. 2009); initially occurring in the home or specialized clinic environments, then moving into both school and other community settings with the goal of the child being integrated into a regular education classroom (Howard et al. 2005; Sallows and Graupner 2005).

During intervention, identified skill deficits are taught by breaking skills down into hierarchical steps and each step is taught with the objective being independent and functional use of the skill within the natural environment. Intervention procedures are based on the principles of behavior analysis and include the use of procedures such as discrimination training, prompting, prompt fading, shaping, chaining, and reinforcement. New skills are taught during structured teaching sessions and practiced during the child's typical daily activities to ensure maintenance and generalization across stimuli, settings, and people. Data are collected during each teaching

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session to document the child's progress. Clinicians supervising EIBI programs for children with ASD meet regularly with the therapy team, which includes therapists, parents, and other service providers, to review techniques being implemented, examine data collected during treatment sessions, provide feedback, introduce new skills, and conduct regular staff training. Additionally, program modifications are made to maximize learning when current teaching procedures are ineffective.

Hayward et al. (2009) discuss four features of effective EIBI, including: (a) treatment intensity, (b) behavior analytic principles, (c) quality supervision, and (d) individualized curriculum. Researchers suggest that it is necessary to implement a minimum of 30 h per week of 1:1 behavioral intervention for at least 2 years to achieve an optimal outcome (Eldevik et al. 2006; Lovaas 1987). The intervention should be based on behavior analytic principles of learning and should be supervised by a clinician with advanced training in applied behavior analysis (ABA) and extensive experience using ABA-based procedures with a variety of children with ASD. Lastly, each child's curriculum should be individualized to address skill deficits and behavioral excesses in every area of human functioning. (American Academy of Child and Adolescent Psychiatry 1999; Hancock et al. 2000; Lovaas 2003). The process of designing individualized curricula is the focus of this chapter.

Designing an individualized curriculum is a multi-step process, including assessment, interpreting the assessment results, and matching lessons to individual needs. This chapter provides a comprehensive description of the process of designing an individualized curriculum (see Table 10.1 for a step-by-step process). The following sections outline vital features of quality assessment, discuss how to link assessment results to curriculum design, and review of some commercially available assessments and curricula that are widely used and may be helpful when designing EIBI programs.

Assessment

The Importance of Assessment

The first step to designing a curriculum for a child with ASD is to conduct a comprehensive assessment to identify skills the child has already mastered and skills the child still needs to learn. Then, this information can be used to design an individualized curriculum that maximizes learning in areas that are functional and relevant in the child's daily life. It is imperative that the curriculum is tailored to the child's specific needs; failing to do so, could potentially result in various adverse side effects.

For example, inappropriate assessment or failing to assess skills could result in designing a "cookbook" curriculum, which is not based on the child's individual needs and involves teaching skills according to a rote step-by-step manual. In this situation, the child may be presented with age-inappropriate lessons or lessons that are too advanced (e.g., the child does not display necessary prerequisite skills). In some cases, the child could even be taught nonfunctional skills that will never be used in the natural environment because they are irrelevant to the child's daily life. Furthermore, the absence of proper assessment is likely to result in a lopsided or unbalanced curriculum design wherein the child's curriculum is too heavily focused in one or two areas without considering other important areas (e.g., perhaps it is focused on academic and language skills without considering social and daily living skills). Ultimately, these issues waste the child's time and hinder progress toward the goal of achieving his or her maximum potential.

Areas to Assess

In order to ensure that the child's curriculum is age-appropriate and well balanced, it is important to administer assessments that address skills in all areas of human functioning from infancy through the child's chronological age. Assessing

Table 10.1 Steps for linking assessment to curriculum

Choose an assessment or battery of assessments. Ideally the assessment(s) should	Conduct assessment and summarize results	Determine skill areas/targets by considering factors such as	Customize or design lesson activities, making sure to
Assess all areas of human functioning		Barriers to learning	Identify the SD, R, and targets
Assess skills from infancy up through the child's chronological age		Level of functioning	Teach language activities by verbal operants
Consider function		Acquisition rate	Consider mastery criteria and generalization
Link to lessons		Functionality of the skill	
Identify strengths and weaknesses		Social validity of the skill	
Track progress		Age of the child	
Allow flexible measurement methods		Prerequisites	
		Pivotal skills and behavioral cusps	
		Complementary skills	
		Treatment hours and duration	
		Treatment provider	
		Resources	

skills that emerge early in life is especially helpful because the child's chronological age oftentimes will not match his or her developmental age (Carey et al. 2009). Children with ASD are often behind in meeting their developmental milestones (Matson et al. 2010); making the assessment of early development essential to determining deficits that must be remediated before a child's skill repertoire is commensurate with same-age peers. Additionally, children with ASD sometimes exhibit advanced skills, yet cannot perform other very basic skills that are important to overall functioning. For example, a child might be able to read books at a level well beyond his or her age, but cannot follow simple instructions.

The identification of skill deficits and strengths across every area of human development allows one to design a well-balanced curriculum that considers needs from each area. Eight key areas of human functioning have been identified including: (1) social, (2) motor, (3) language, (4) adaptive, (5) play, (6) executive functions, (7) cognition, and (8) academic skills (Gould et al. 2011). What follows is a description of each of these areas.

Social Dating back to Leo Kanner's original descriptions of autism in 1943, deficits in social skills were emphasized and today remain one of the defining features of ASD (5th ed.; DSM-V; American Psychiatric Association [APA] 2013). It is viewed as a core feature of ASD (Constantino and Gruber 2005) and is one of the main focuses of treatment (Torres et al. 2003). Social deficits in children with ASD are quite variable (Constantino et al. 2003); but often include eye contact, use of appropriate gestures and facial expressions, and initiating and reciprocating social interactions (Bishop et al. 2007). Difficulties with social skills will impact many important areas of a child's life, such as making friends, maintaining a job, and building confidence and self-esteem; thus, this is an essential element to the treatment of autism.

Motor Deficits in motor behavior are not a defining feature of ASD, however, researchers have reported that children with ASD often present with delays in motor skills (Dewey et al. 2007; Dyck et al. 2007; Miyahara et al. 1997; Page and Boucher 1998). Specifically, researchers have documented deficits in gross motor skills (Berkeley et al. 2001; Dyck et al. 2007; Jansiewicz et al. 2006; Provost et al. 2007; Teitelbaum et al. 1998), fine motor skills (Berkeley et al. 2001; Dyck et al. 2007; Ghaziuddin and Butler 1998; Lopata et al. 2007; Manjiviona and Prior 1995; Noterdaeme et al. 2002; Page and Boucher 1998; Provost et al. 2007), oral motor skills (Adams 1998; Amato and Slavin 1998; Gernsbacher et al. 2008; Page and Boucher 1998), and visual motor skills (e.g., Kurtz 2006; Lopata et al. 2007; Rosenhall et al. 1988; Scharre and Creedon 1992).

Gross motor skills involve large body movements such as kicking, jumping, and catching; whereas, fine motor skills encompass smaller body movements, usually with the hands and fingers, such as grasping, picking up small objects, and holding a pencil correctly. Oral motor skills require moving the tongue, lips, and other parts of the mouth correctly in an effort to produce related speech sounds. Visual motor skills involve ocular motility (eyes working smoothly together as in fixation, tracking, and scanning), binocular vision skills (using both eyes simultaneously to view objects and combine what is seen by each eye into a single image), and visual perception (Kurtz 2006).

Language Language deficits are another defining feature of ASD. The language deficits characteristic of ASD are broad and include but are not limited to: delays in speech, making requests, labeling objects, and conversation skills (Tager-Flusberg 1981; Kjelgaard and Tager-Flusberg 2001). Language development allows a child to learn to effectively communicate with and comprehend the communications of others, making it an integral component of human behavior. These skills are directly associated with social interactions, play skills, and many academic skills. Deficits in language skills can adversely impact a child's life by impeding his or her development in all of these areas. In fact, in some cases, inappropriate behavior develops as a means of communication when appropriate language skills are lacking (see Durand and Merges 2001 and Mancil 2006 for reviews of functional communication training). Given the central role that language skills play in an individual's ability to effectively communicate, participate in social and play interactions, and succeed academically, it is clear that a large proportion of time must be dedicated to the development of language skills in children diagnosed with ASD.

Adaptive Deficits in adaptive behavior are not a defining feature of ASD; however, delays in adaptive skills are common for many children with ASD (Carpentieri and Morgan 1996; Liss et al. 2001; Lord and Schopler 1989). Adaptive behavior includes daily living activities such as personal skills (dressing and toileting, etc.), domestic skills (setting and clearing the table, making the bed, etc.), community skills (shopping, restaurants, etc.) and safety skills. Difficulties with adaptive skills will impact an individual's ability to live independently, become involved in community activities, and participate in a typical classroom setting; thus, it is essential to remediate deficits in adaptive behavior.

Play Deficits in play skills are a defining feature of ASD. Deficient play skills will impact an individual's ability to interact with same-age peers, appropriately fill alone and leisure time, and develop skills across a range of domains important for later in life. Through play, children develop and hone critical skills such as confidence, emotional control, fine and gross motor abilities, language, and social competence (Boutot et al. 2005). In children with ASD, play skill deficits manifest as a failure to engage in varied and spontaneous make-believe or social imitative play appropriate to the child's developmental level (*DSM-V*; APA 2013). For example, young children with ASD may not show interest in independent play toys such as blocks, shape sorters and musical toys typically preferred by same-age peers, and/or may engage with play items in an inappropriate or restricted manner, such as spinning and gazing at the wheels of toy vehicles, or repetitively viewing scenes from books or television shows.

Executive functions Deficits in executive functioning are not a defining feature of ASD; however, researchers have documented delays in executive functioning skills for some children with ASD (Pennington and Ozonoff 1996). Executive function refers to the cognitive processes used in goal-directed behavior such as planning and organizing, initiating a task, attending properly (attending to the correct stimuli, sustaining attention toward a goal, multitasking, shifting attention between tasks, etc.), using inhibition to stay focused, working memory, monitoring performance, problem solving, and demonstrating flexibility by the willingness to generate alternative solutions and plans as needed (Dawson and Guarre 2004). This is an important developmental area for children with ASD because it is these types of skills that allow children to regulate themselves. Specifically, these are the skills that help them to organize themselves and make plans to reach goals that require them to forgo immediate rewards for long-term rewards, determine what stimuli are important to attend to versus ignore, and manage their emotions and performance so that they can work as effectively and efficiently as possible.

Cognition Deficits in cognition are not a defining feature of ASD according to the *DSM-V* (APA 2013); however, children with ASD have been reported to often present with delays in cognitive skills (Baron-Cohen et al. 2000). Deficits in this area have been reported to exist both in understanding the mental states of oneself (metacognition) and others (social cognition; also sometimes referred to as perspective taking; Baron-Cohen et al. 1985; Baron-Cohen et al. 2000; Leekam and Perner 1991; Ozonoff and Miller 1995). Understanding mental states such as one's thoughts, desires, intentions, beliefs, emotions, and preferences, to name a few, is important for developing a strong perspective-taking repertoire essential for successful social interactions. For example, development of this type of repertoire has been suggested to play an important role in many social behaviors such as pretense, sharing, turn taking, self-consciousness, self-reflection, persuasion, empathy, and deception (Frith et al. 1994; Howlin et al. 1999; Lalonde and Chandler 1995).

Academic Deficits in academic behavior are not a defining feature of ASD according to the *DSM-V* (APA 2013); however, some children with ASD display academic learning difficulties. Researchers have reported that learning disabilities are prevalent among children with ASD (Mayes and Calhoun 2006; Montes and Halterman 2006). For instance, Mayes and Calhoun reported that 67 % ($n = 124$) of the children they evaluated with ASD also displayed a learning disability. Difficulties with academic skills will impact an individual's ability to independently participate in and complete academic assignments at school. The academic skills deficits displayed by children with ASD vary from child to child and may include delays in reading, math, spelling, and written expression.

Choosing Assessments

There are many variables to consider when choosing assessments. Assessments that contain the following characteristics will be most helpful for clinicians using them to design EIBI programs (Gould et al. 2011).

Comprehensive scope To guarantee the assessment of every skill typically observed from infancy through the child's chronological age, a comprehensive assessment must be used. When a comprehensive assessment is not available, it becomes necessary to use a battery of assessments to ensure that no skills are overlooked and all areas of human functioning are assessed. Data collected during the comprehensive assessment or battery of assessments will be used to formulate a well-balanced and individualized treatment curriculum.

Categorized by age EIBI treatment should begin as early as possible with a goal of successful integration into a classroom; therefore, assessments selected should be suitable for use with very young children (i.e., 6 months or less) up to first or second grade (approximately 7 or 8 years old). Items within the assessment(s) should be age appropriate for the child being assessed and should progress by age of typical development. Ideally, assessments will be age-normed or at least provide developmental markers grounded in empirical research.

Considers function Programs based on a functional analytic approach have yielded effective treatment outcomes for young children with ASD (Perry et al. 2008). Since a child might use the same behavior in many different ways, determining the function of the behavior is considered as important as what the behavior looks like. By considering both behavior function and topography, assessment results in the formulation of an individualized curriculum that is developmentally and functionally appropriate for each child's strengths and areas of need. This is particularly relevant in the assessment of language. Specifically, Sundberg and Michael (2001) suggest that greater gains could be observed if the use of Skinner's (1957) functional behavioral approach to language was more widespread.

Skinner (1957) argues that verbal behavior (language) is primarily influenced by environmental factors or learning history (e.g., motivation, reinforcement and punishment). The unit of analysis is the verbal operant, of which seven primary operants were identified by Skinner (1957): (1) Mand, (2) Tact, (3) Echoic, (4) Intraverbal, (5) Textual, (6) Transcriptive, and (7) Copying a text. Each operant is a functionally different type of language that is readily understood in terms of basic behavioral principles. All consist of relationships between motivational operations, discriminative stimuli and response forms, and are developed through the occurrence of response-contingent consequences. A set of verbal operants make up the verbal repertoire of an individual.

The categorization of language by verbal operant types (i.e., function) is important because it ensures that we are not just teaching the meaning of words associated with traditional receptive language (i.e., behavior indicating the child "understands" spoken language as in when told "touch apple" the child locates the apple in an array of stimuli) and expressive language (i.e., behavior indicating the child is using the language in an expression as in when asked "What is it?" the child says, "apple"). Traditional instruction in receptive and expressive language does not guarantee that the child will later be able to use language in various situations, such as when hungry and wanting to request an apple (mand), or when seeing an apple growing on a tree and pointing it out to another person and saying "Look, an apple!" (tact), or when the child is asked to name his or her favorite fruit during a conversation and the child says, "Apples!" (intraverbal). Each of these functional uses of language may need to be taught separately, and assessments should strive to ensure they are individually evaluated.

Links to lessons A major strength of an EIBI assessment instrument is a direct link between the identification of specific behaviors to teach and curricular targets. Behavior analytic interventions are based on operationally defined target behaviors; however, many assessments only yield quotients or overall scores within different domains or skill areas that are not directly linked to curriculum plans. Such assessments may not provide enough specific information to guide the design of an individualized behavioral treatment curriculum. Clinicians are left to interpret quotients or overall scores, and continued assessment is often needed to determine exactly what to teach within each skill domain. For example, an assessment may reveal deficits in independent play skills but will not identify any particular types of independent play to target (e.g., symbolic play, construction play, functional pretend play, etc.) or any specific components of play that the child is struggling with (e.g., imitation of play movements, narrating play, joining and initiating play, etc.).

Identifies strengths and weaknesses Assessments should identify skill deficits and strengths within each skill domain. This will help clinicians prioritize treatment targets and determine which skills should be taught first. For example, an assessment may reveal that a child can independently ask for preferred items using one-word phrases but does not use modifiers (e.g., “big,” “more,” etc.). A starting point for the expansion of manding (requesting) behavior might be teaching the child to add simple modifiers to one-word phrases. Identifying strengths and interests can also help guide teaching strategies. For example, if the child is a strong sight-reader, a clinician might incorporate written prompts into teaching procedures.

Tracks progress It is critical that assessments can be used to track child progress over time. EIBI programs are grounded in ongoing measurement and analysis of treatment effects. Repeated administration of an assessment will contribute to a comprehensive picture of changes in a child’s learning. Ideally, the administration of assessments should be cost-effective, time efficient and relatively easy to administer repeatedly, while presenting a reliable and valid picture of the child’s individual skills at any given time. An assessment that is complicated or cumbersome to administer, expensive and/or time consuming, with results that are difficult to interpret, is less likely to be administered by clinicians regularly and less useful for tracking child progress and treatment effectiveness.

Flexible measurement methods Assessments should be able to be administered using both direct and indirect methods. Direct assessment or direct observation is generally considered the ideal method of measurement within ABA programs (Cooper et al. 2007). The benefit of direct observation is that it provides direct information regarding the behaviors or skills that a child actually displays, rather than relying on third-person reports about what a child may have done or be able to do. However, there are also a number of limitations associated with direct observation. In many treatment settings, direct observations may be impractical. To be certain that direct observation yields a representative sample of behavior, direct observation requires objectively defined behaviors to be observed systematically during scheduled intervals and durations by trained observers (Sigafoos et al. 2008). Further, since direct observation is reliant on human observers, only a few behaviors can be assessed at any one time if reliable results are to be achieved (Matson 2007). To observe and assess every skill that emerges from birth up to the child’s chronological age, across all areas of human development, would take a great deal of time and effort (especially in the case of an older child), making direct observation of these skills unrealistic in most clinical settings. Given these limitations, clinicians may not be able to rely solely on direct observation to obtain a fully comprehensive skill assessment.

The alternative to direct observation is indirect assessment. Indirect assessment involves asking informants familiar with the child (e.g., parents, teachers or clinicians) to make judgments regarding specific behaviors or skills over some time frame (e.g., the past 1–3 months), in order to provide an estimate regarding the child’s skill repertoire. Common indirect assessment tools include rating scales and checklists. Checklists involve recording whether skills are present or absent from a child’s repertoire, whereas rating scales specifically measure the frequency and/or severity of skill deficits and behavioral excesses.

Indirect assessment has several advantages. It generally requires less time and effort to administer than direct observation methods and the data it yields may be less influenced by transient environmental variables than data collected through direct observation (Sigafoos et al. 2008). That is, indirect assessment may better accommodate behavior variability, whereas it could take several repeated observations to obtain a true picture of a behavior or skill over time. A disadvantage of indirect methods of assessment is that their reliability and validity are questionable since results are based on the informant’s idiosyncratic interpretation of the meaning of items and ratings (Sigafoos et al. 2008). However, indirect assessment may be the only reasonable route to take given the vast amount of time and resources that would be required to obtain a comprehensive skill assessment via direct observation. An ideal compromise would be to supplement a comprehensive indirect assessment with direct observation data, for example when informants are unsure of the answer to a given item.

Table 10.2 Assessments for Early Intensive Behavioral Intervention

Assessment component	ABLLS®-R	Brigance® IED-II	Brigance® CIBS-R	Skills®	VABS™	VB-MAPP
Domains addressed	6	6	1	8	5	5
Language	X	X		X	X	X
Social	X	X		X	X	X
Adaptive	X	X		X	X	
Academic	X	X	X	X		X
Executive function				X		
Cognition				X		
Motor	X	X		X	X	X
Play	X	X		X	X	X
Target age range	Not mentioned	0–7 yrs	K–9th	0–adolescence	0–90 yrs	0–4 yrs
Categorized by age		X	X	X	X	X
Considers function	X			X		X
Linked to lessons	X[a]			X		
Identifies strengths and weaknesses	X	X	X	X	X	X
Tracks progress	X	X	X	X		X
Measurement Method	Indirect/Direct	Indirect/Direct	Indirect/Direct	Indirect/Direct	Indirect	Indirect/Direct
Psychometrics			X	X	X	

[a] Linked to The Big Book of ABA Programs

Gould et al. (2011) identified four assessments that most closely address the above key elements of an assessment used for designing EIBI programs (for a full review of assessments, see the manuscript), including: The Verbal Behavior Milestones Assessment and Placement Program (VB-MAPP; Sundberg 2008), The Vineland Adaptive Behavior Scales-Second Edition (VABS-II; Sparrow et al. 2005), The Brigance Diagnostic Inventory of Early Development-II (Brigance IED-II; Brigance 2004), and The Brigance Comprehensive Inventory of Basic Skills-Revised (CIBS-R; Brigance 2010). In addition to these, the Assessment of Basic Language and Learning Skills—Revised (ABLLS®-R; Partington 2008) and Skills® (which has become available since the time of the Gould and colleagues review) address three or more of the key elements discussed in the Gould paper (refer to Table 10.2 to view the traits of ABLLS®-R, Skills®, and the four assessments identified by Gould and colleagues).

Linking Assessment to Curriculum

Following a comprehensive assessment, selecting and prioritizing teaching targets can seem like a difficult task, particularly since children with ASD often have extensive skill deficits across multiple areas of development. In addition, clinicians are faced with practical limitations imposed by funding, treatment duration, availability of client and trained professionals, and family resources. It is crucial that clinicians prioritize treatment targets and manage resources carefully if they are to ensure the best outcome for each child. What follows are a series of steps and considerations that will occur in an effort to design an individualized curriculum for each child.

Step 1: Summarize Results

The first step in utilizing the results of an assessment to design a curriculum is to summarize and interpret the results of the assessment in an effort to determine areas of strength and weakness for the child. The assessment should provide some sort of depiction of how the child is functioning across each of the areas of child development. The results are usually summarized either by scores or age equivalence, and may or may not be accompanied by charts or graphs that visually depict how the child is performing in each area assessed. Clinicians should follow the instructions of the assessment for summarizing the results and then examine them closely.

Step 2: Determine Skill Areas/Targets

A fully comprehensive assessment should identify any skills that are already in place as well as the child's strengths, weaknesses, and interests. Clinicians can capitalize on this information to optimize learning, for example, by building on areas of strength initially before moving to other skill areas. More specifically, the assessment process should identify how far behind the child is overall in each developmental area (e.g., is performing at a mental age of 3 for language and 2 for play) and with respect to specific skill deficits in each developmental area (e.g., language concepts particularly lacking include using negation, categorizing, etc.). Clinicians should be able to interpret the assessment results to identify areas in which the child displays more or less skills than others and to gain a complete picture of how the child is functioning overall across all areas of development. Once this information is obtained, many different factors need to be considered in an effort to decide areas of focus during intervention and how much emphasis to put into each of them.

Barriers to learning One of the first factors to consider is whether the child exhibits any severe challenging behaviors that need immediate attention, in particular, any that might affect the safety of the child and others. In the event that the child is engaging in severe challenging behaviors to a level that impedes the ability to teach the child skills, treatment programs will initially focus on the reduction of severe problem behaviors and teaching alternative, replacement behaviors before starting to focus on other skills.

Similarly, clinicians should identify and address barriers such as less severe challenging behaviors or skill deficits that will interfere with the child's ability to learn new skills. For example, frequent stereotypical behaviors that compete with attending, few or no effective reinforcers, and complete noncompliance are all barriers that would need to be the initial focal points of treatment for some children. Other barriers might include lack of instructional control and discrimination skills, and deficits in other core learning skills such as verbal imitation, motor imitation, scanning skills, visual perceptual skills, and so on. The challenge will be to determine what the child's barriers are and to ensure that each of them is addressed by a lesson within the curriculum designed for the child.

Level of functioning The child's level of functioning and the presence or absence of basic skills is also a major consideration when planning areas to target. Clinicians should consider the importance of one skill over another, focusing on establishing basic functional skills before working on less functional skills. For example, typically one will prioritize skills such as communicating basic wants and needs, following simple instructions, engaging in basic independent activities (to occupy time appropriately during the day) and performing basic self-care tasks such as feeding and toileting.

Acquisition rate It is also important to consider the child's acquisition rate when prioritizing skills of focus. For children who learn more slowly or struggle to master skills, one might consider introducing fewer targets at once or to concentrate on foundational skills rather than more complex skills. The amount of time it will take to master a skill and how likely clinicians are to be successful in establishing a skill are important variables to consider when optimizing the use of limited resources. Some skills will be more difficult to establish than others. If a skill will take a child a long time to master, this could impact the teaching of other important skills. For example, if a child struggles with establishing new skills, introducing more difficult abstract concepts such as colors or prepositions is likely less of a priority than teaching other skills such as choices or developing basic receptive and expressive language skills.

Functionality of the skill Clinicians should consider how useful or functional a skill is for the child compared to other skills (i.e., how likely it is for the skill to be maintained in the natural environment) as well as how many opportunities the child will have to use the skills learned. Only targets that are likely to produce reinforcement in the child's natural environment once treatment ends should be selected, since these are the skills that are most likely to be maintained and benefit the child in the long term (the "relevance of behavior rule"; Ayllon and Azrin 1968).

Social validity As well as considering the functionality of a skill, clinicians should consider "social validity" or "social significance" of selected targets (i.e., how acceptable or important a particular behavior is to consumers) (Cooper et al. 2007). Skills that will produce immediate benefits to the child, as opposed to skills that might produce benefits at some time in the future should be considered. For example, working on requesting (manding) would be prioritized over working on ordering numbers from 1 to 20.

Considering benefits to the child should be first priority, however, it is also important to consider the priorities of other family members and what will most impact the entire family's daily life. For example, safety or self-help skills may be a much greater priority over academic or social skills. Skills that will immediately benefit the child and family by enabling the integration of the child into key educational or social environments or that will help him or her access upcoming life events (e.g., family holiday events, starting school, going to a birthday party, visiting the doctor or dentist, etc.) should be considered. For example, working on flexibility related to changes in routine, building the child's ability to wait, working on transitioning appropriately to and from the car, and so on, may help a child cope with some of the challenges of a family holiday. Enabling the child to better access key educational, social or community environments will provide the child with new learning environments and exposure to learning opportunities that he or she did not have before.

Age of the child When choosing targets, it is important to consider the child's chronological age and the developmental progression of skills; typically clinicians will teach skills associated with a younger age first and work upwards. Clinicians should also always keep in mind what is age appropriate for the child (i.e., what activities and materials/objects his or her same-age peers use and desire as well as places they frequent). The concept or philosophy of "normalization" has become increasingly important in the treatment of persons with developmental delays (Nirje 1985). Normalization emphasizes helping people with disabilities to socially and physically integrate into mainstream society as far as possible (Cooper et al. 2007). This can be a challenge when a child's abilities are severely impaired, but clinicians should do their best to consider chronological age appropriateness.

Prerequisites Identify whether particular behaviors or skills are prerequisites to other important skills and whether skills taught at one point in time will facilitate the mastery of other skills later. Such skills should be prioritized for treatment. For example, nonvocal imitation, eye contact, stimulus orienting and compliance are necessary for learning many other skills.

Certain skills can appear to be unimportant, but may be stepping-stones or "building blocks" toward more useful or complex skills. Building blocks are essentially teaching steps that may or may not be necessary for a particular child to learn in order to master a fundamental skill (a core skill that a child needs and uses during daily life). For example, the skill of matching or sorting pictures of body parts may not seem particularly functional but may be a building block toward being able to receptively identify body parts on oneself and others.

Typically, one would introduce any necessary building blocks before working on fundamental skills. It is important to remember that every building block will not need to be addressed with every child; they should only be introduced if clinically appropriate. Once necessary building blocks and fundamental skills are mastered, clinicians could consider working on "expansion skills" if appropriate (more advanced level skills that build core fundamental skills to enrich a child's functioning level in a particular area). For example, once a child has established the fundamental or core skill of "same/different" and the child is able to request something that is the same/different from what is being offered (e.g., "I want a different one" or "I want the same"), the clinician might further develop the child's skills so that the child begins to relate requests to a specific person (e.g., "I want the same as Hannah").

Pivotal skills and behavioral cusps Within the field of behavior analysis, two concepts highlight the benefits of taking a building block approach to skill acquisition: *pivotal skills* (Koegel and Koegel 1988) and *behavioral cusps* (Rosales-Ruiz and Baer 1997). Pivotal skills are considered behaviors, that once acquired, result in changes in other functional, untrained behaviors. When pivotal areas are strengthened, improvement in autonomy, self-learning, and generalization of new skills will follow (Koegel et al. 1999). For example, increasing a child's ability to initiate interactions with others may result in increased use of language and the emergence of other response classes such as asking questions (Koegel et al. 2003). Joint attention could also be considered a pivotal skill since its development may contribute to improvement in many other untargeted social and language behaviors (Jones et al. 2006). Koegel et al. (2003) highlight the benefits of working on pivotal skills to both the child and the clinician. For the child, targeting pivotal skills may shorten treatment, make learning more efficient, and provide new repertoires of behavior and increased contact with reinforcers. For the clinician, teaching time could be decreased and increased generalization achieved.

A behavioral cusp is defined by Rosales-Ruiz and Baer (1997) as, "a behavior change that has consequences for the organism beyond the change itself, some of which may be considered important" (p. 537). For example, generalized imitation would be considered a behavioral cusp because it provides the child (and clinician) with a gateway to the acquisition of many new important skills (Young et al. 2011). Bosch and Fuqua (2001) suggest that a behavior can be considered a cusp if it: (a) provides access to new reinforcers, contingencies, and environments, (b) is socially valid,(c) results in generativity, (d) competes with inappropriate behaviors, and (e) affects a number of people in an important way. Crawling is another example of a cusp because it enables children to independently move around their environment, bringing them into contact with a wealth of new interactions and learning opportunities that they did not have access to before. Cusps can be simple or complex, easy to establish or effortful, but all share wide-reaching and important behavior change outcomes. Cusps can be universal or child specific; "one child's cusp may be another child's waste of time" (Rosalez-Ruiz and Baer 1997, p. 541). The clear advantage is that, by identifying and targeting behavioral cusps, clinicians can bring about subsequent important behavior changes that were not formally programmed but may have a huge impact on a child's skill acquisition.

Complementary skills Skills from different curricular areas should ideally connect or complement each other where possible, with communication and socialization goals being interwoven into all lessons across curricula. For example, when developing independent play skills and teaching the child to complete a variety of task completion activities such as puzzles or shape sorters, the child might also be working on developing fine motor skills needed to effectively manipulate play items, using an activity schedule, initiating or requesting play activities, making play choices, and so on.

Treatment hours and duration The number of therapy hours available and the potential duration of intervention will impact the selection of curricular targets. Clinicians who are working against a time limit (for example the child starting school or access to limited funding) will prioritize skills that the child and family most need to achieve within this time. A greater number of available therapy hours will allow for more skill targets to be addressed. In our practice, we typically select 15 to 20 targets for children receiving 30 h of therapy per week, and between 20 and 25 targets for children receiving 40 h of therapy per week. For children receiving less therapy hours, we usually select fewer skill targets to address at any one time—generally no more than ten targets for 15 h of therapy per week.

A higher number of therapy hours should result in a treatment program that is comprehensive (i.e., includes target skills from all developmental areas), whereas fewer therapy hours will likely mean a narrower focus on key areas of need (e.g., concentration on communication and self-help skills). However, every child is different, so the actual number of targets or lessons in acquisition at any one time may be more or less than the guidelines above and the focus of treatment targets will vary.

Funding sources sometimes dictate not only the number of therapy hours and duration of treatment, but also the specific goals or skill areas that should to be targeted during treatment. Likewise, there may also be restrictions on how therapy is delivered, for example, whether therapy is delivered in home or in school, the qualifications of therapists who can be hired, whether a parent has to be present during sessions, and so on. All these are factors that will influence the design of a child's treatment plan.

Treatment provider The individual who will be delivering therapy is a further factor to consider when designing a treatment plan. Therapy may be delivered by a team of therapists, volunteers, teacher's aides, family members and so on, all of whom will have different skill sets and expectations. Different team members will thus require varying levels of training and supervision. Some may require substantial time and effort to ensure they are able to implement certain lessons effectively. If time and resources for training and supervision and expertise is limited, clinicians may need to prioritize more simple lessons over more complex ones.

Another variable will be the availability of different team members. Some may only be available for limited hours, at certain times, on certain days of the week. This may influence which targets you are able to work on or which skills are likely to be established effectively. Team members may also vary in the types of activities or skills they are willing to address. For example, some therapists may not feel comfortable carrying out community outings or potty training.

Resources Finally, clinicians should consider whether the therapy team will have access to the resources needed to teach certain skills. Limitations in terms of resources may make establishing certain skills more difficult. For example, if therapists only have access to limited teaching materials and new materials are hard to come by, it may take a really long time to teach or generalize particular targets. Or, if the child only has sporadic access to peers, it may be difficult to establish peer-related skills. Likewise, if it is not possible to schedule outings, it may be difficult to establish community skills. Also important is the availability of resources to ensure generalization of a newly taught skill (e.g., access to different people, settings, materials/stimuli and so on).

Step 3: Design Lesson Activities

Once the deficit areas identified by assessment have been factored against all of the critical considerations needed for determining areas of focus (as outlined above), the next step is to either consult existing curricula to find lessons that have already been designed to teach the related skills and tailor them to meet the child's needs or design lessons from scratch that meet the child's needs.

Identify the SD, R, and targets When customizing or designing lesson plans for each child, skills will need to be broken down into activities with small enough units to ensure mastery. Clinicians should consider exactly what behavior they want the child to learn to do (i.e., what the behavioral goal is) and exactly what they need to track in order to decide whether that behavior has occurred or not. Lesson activities will need to be observable, measurable, and individualized for the particular child.

Each activity should also include specific information regarding (1) the environment(s) in which the skill will be displayed, (2) with whom the skill will be displayed, (3) the materials or set up that will be in place, (4) any setting events or establishing operations (EOs) that will be in effect, (5) the discriminative stimulus (SD), and (6) the response (R) expected.

For some activities, clinicians will also need to identify all individual targets associated with the particular activity that will need to be taught if the child is to master the activity at an age-appropriate level. For example, when teaching number identification, the activity might be presenting number cards and asking the child "What number?" (this is the general SD) and expecting the child to name the number (this is the R), but the targets that need to be mastered include numbers up to 9 for 4 to 5 year olds, up to 31 for 5–6 year olds, up to 100 for 6–7 year olds, and up to 1,000 for 7–8 year olds.

Teach language activities by verbal operant When designing language lessons, it is also important to take a functional approach. Verbal behavior is a critical part of most major aspects of human life, including language acquisition, social interactions, perspective taking, problem solving, academics, and so on (Cooper et al. 2007). Language deficits are a key feature of children with ASD, thus language development is seen as a major goal of EIBI programs. Generating language in children with ASD poses great challenges for clinicians attempting to devise effective interventions.

Sundberg and Michael (2001) argue that the verbal behavior approach to language suggests clinicians should identify and develop all relevant verbal operants when selecting deficit areas for intervention and avoid assuming that development of one operant will result in the development of others. Essentially, this translates into ensuring that all relevant verbal operant types are being addressed when teaching language concepts. For example, when teaching the child the action label "eat" and/or "eating," the clinician would ensure that the child can: (a) use "eat"/"eating" when making a request, as in, "I want to eat" (mand), (b) use "eat"/"eating" when labeling an action, as in, "The boy is eating" (tact), and (d) use "eat"/"eating" in conversation, as in, responding to the question "What are you doing?" with, "I'm eating" (intraverbal). To ensure this outcome, the clinician would deliberately arrange activities to teach each individual verbal operant type for every language concept and not assume that teaching the child receptive (responding to the instruction, "Touch 'eating' " by touching a picture of someone eating in an array of pictures) and expressive language (responding to the question "What is he doing?" with "He's eating") will automatically result in the emergence of each other verbal operant type.

Consider mastery criteria and skill generalization Throughout the process of choosing targets and designing lessons, clinicians should consider what criteria must be met in order for a target skill to be truly mastered. Criteria will depend on the child's specific learning profile and the skill that is being taught. The goal is that the child reaches a level of competence that ensures the skill will be functional or useful and will continue to be maintained by reinforcement contingencies present in the child's natural environment. Further, the skill should ideally be demonstrated at a competence level similar to the child's typically developing peers. Clinicians should be flexible and adjust mastery criteria as clinically appropriate; some children may struggle to reach criteria consistently while others reach and maintain criteria easily. Thus, it is important to continuously review data to evaluate teaching effectiveness and conduct frequent observations of the child in his or her natural environment (since data alone may not give the whole picture regarding a child's learning profile).

A final, but important, consideration for clinicians is to ensure that there is programing in place for achieving skill generalization and maintenance. A newly taught skill is not useful for the child if he or she does not demonstrate it across appropriate people, situations, and settings, or when the skill is demonstrated in a restricted, inflexible way. Thus, throughout the curriculum design process, clinicians should be thinking about how they will ensure that chosen targets will be generalized and maintained. It is beyond the scope of this chapter to discuss strategies for promoting generalization, instead we refer readers to Stokes and Baer (1977) for a discussion on programming for generalization, and Cooper et al. (2007) for some guiding principles that may further enhance generalization and maintenance strategies.

Commercially Available Curricula

There are several different curricula commercially available, many with teaching units that are either already in SD and R format or can be easily transferred into that format, which might be useful when designing individualized treatment lessons. What follows is a review of curricula that are either widely used or are what we believe to be most useful for programming in the eight developmental areas outlined in this chapter. For the current review, curricula are described in terms of the utilized approach, population for which they were designed, curricular content, and empirical support (when applicable). Furthermore, Table 10.3 highlights: (a) developmental areas addressed, (b) age range of the curriculum, (c) whether the curriculum provides prerequisites required for lesson activities, (d) whether the activities correspond to specific questions in an assessment, (e) whether the curriculum is broken into teaching levels or are presented in a developmental sequence (i.e., provides a way of determining lesson activities that are basic, beginner level versus those that are advanced), (f) whether the language curriculum is organized by verbal operant types, (g) whether the curriculum provides lesson plans, and (h) whether there are graphs or charts to visually depict a child's progress through the curriculum.

Autism Curriculum Encyclopedia (ACE®)

Autism Curriculum Encyclopedia (ACE® (http://www.acenecc.org); version 3) is a web-based program intended for teachers and professionals to design behavioral intervention programs for children and adults with ASD. It includes a Core Skills Assessment used to assess 48 foundational skills. The ACE® comprises over 1,500 customizable lesson plans (129 of which are linked to Core Skills Assessment items) outlining instructions across the following domains: communication, self-help, discrimination, social skills, recreation and physical education, health and safety, community, academics, and vocational skills. The ACE® also includes a set of preference assessment tools that help teachers to identify positive reinforcers for use in teaching sessions and a system for tracking data on challenging behavior and important events. Data from teaching sessions can be recorded using ACE® Mobile, which is available for iPhone and iPod Touch devices, or may be recorded on paper and later entered using a desktop or laptop computer. Once entered, data from teaching sessions may be viewed in a table or graphical format, and the system produces reports of performance on assessments and challenging behavior.

Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals

Behavioral Interventions for Young Children with Autism: A Manual for Parents and Professionals (Maurice et al. 1996) was designed to guide parents and practitioners through early intervention programs. The manual emphasizes securing scientific supported behavioral treatments initiated at an early age to yield the best outcomes. Chapters include outlining what skills should be taught, teaching strategies, and selecting

Table 10.3 Curricula for early intensive behavioral intervention

Features	ACE®	Behavioral intervention for young children with autism	Carolina curriculum	Crafting connections	Do-Watch-Listen-Say	Eden	IGS	Language for learning	Making a difference
Domains addressed									
Language	X	X	X		X	X	X	X	
Motor	X		X			X	X		
Adaptive	X	X	X			X	X		
Social	X	X	X	X	X	X	X		X
Play	X		X		X	X	X		
Academic	X	X	X			X	X	X	
Executive Functions									
Cognition				X					
Ages	18 mos.–adult	EIBI	Birth–5 yrs	Children–adolescence	Young children	Infant–adult	Not mentioned	4 yrs–primary grades	Not mentioned
Prerequisites	X	X		X		X			X
Linked to Assessment	X		X		X	X		X	
Teaching Levels/ Developmental Progression	X	X	X	X		X	X	X	X
Verbal Operants	X			N/A					N/A
Lesson Plans	X	X	X	X	X	X		X	X
Graphs/Charts	X		X			X		X	

Features	ME Book	Rethink autism™	Skills®	Skillstreaming	STAR™
Domains addressed					
Language	X	X	X		X
Motor		X	X		
Adaptive	X	X	X		X
Social		X	X	X	X
Play	X	X	X		X
Academic	X	X	X		X
Executive Functions			X		
Cognition			X		
Ages	EIBI	Children–adolescence	Birth–adolescence	Preschool–adolescence	2–12 yrs
Prerequisites			X		Some
Linked to Assessment		X	X		X
Teaching Levels/ Developmental Progression	X		X	X	X
Verbal Operants		X	X	N/A	
Lesson Plans	X	X	X	X	X
Graphs/Charts		X	X		

Features	Syracuse community-referenced curriculum guide	Teaching children with autism to mind read	Teaching individuals with developmentaldelays	Teaching language to individuals with developmental delays
Domains addressed				
Language	X		X	X
Motor	X			
Adaptive	X		X	
Social	X			
Play	X		X	
Academic	X			
Executive Functions				
Cognition		X		
Ages	K[a]–21 yrs	Not mentioned	EIBI	Not mentioned
Prerequisites				
Linked to Assessment	X			
Teaching Levels/ Developmental Progression	X	X	X	X
Verbal Operants		N/A		X
Lesson Plans		X	X	
Graphs/Charts				

[a] K stands for Kindergarten.

Features	Teach me language	The big book of ABA programs	Think social!	Work in progress
Domains addressed				
Language	X	X		X
Motor		X		X
Adaptive		X		X
Social		X	X	X
Play		X		X
Academic	X	X		X
Executive functions				
Cognition			X	
Ages	K–adolescence	Up to K	K and up	Not mentioned
Prerequisites				some
Linked to assessment		X		
Teaching Levels/ Developmental progression			X	X
Verbal operants		X	N/A	
Lesson plans	X	X	X	Some
Graphs/Charts				X

behavior change agents. Beginning, intermediate, and advanced language, social, adaptive and academic skills are presented (covering basic, key skills within each) to aid the formulation of an appropriate teaching program.

Carolina Curricula

The Carolina Curricula include two volumes: The Carolina Curriculum for Infants and Toddlers with Special Needs (CCITSN; Johnson-Martin et al. 2004) and The Carolina Curriculum for Preschoolers with Special Needs (CCPSN; Johnson-Martin et al. 2004). The curricula are developmental (this is one of the only curricula reviewed in this chapter that provides ages for each skill), but behavioral theory and methodology are influential in the construction of lesson activities. Both were designed to be used by teachers and professionals for assessing and treating children with special needs. The CCITSN focuses on over 500 skills from birth to 3 years; whereas the CCPSN addresses over 400 skills from 2 to 5 years. Both versions offer assessment and curriculum for teaching basic, key skills related to social, motor, language, adaptive, play, and academic skills. Assessment results correspond to specific intervention targets and teaching activities which can be introduced based on identified strengths and weaknesses. Both curricula also include assessment logs and progress charts to record data and evaluate progress.

Crafting Connections: Contemporary Applied Behavior Analysis for Enriching the Social Lives of Persons with Autism Spectrum Disorder

Crafting Connections: Contemporary Applied Behavior Analysis for Enriching the Social Lives of Persons with Autism Spectrum Disorder (Taubman et al. 2011) uses a behavior analytic approach to teaching social skills to individuals with ASD. The curriculum includes lessons for teaching a broad range of social skills and some cognition skills in five domains: social awareness, social communication, social interaction, social learning, and social relatedness. Crafting Connections also provides direction regarding assessment and curriculum development, social skills groups, socialization and adolescence, true friendships, and methods of instruction.

Do-Watch-Listen-Say

Do-Watch-Listen-Say (Quill 2000) combines behavioral and developmental approaches to assessment and curriculum designed for educators targeting social, play, and communication skills in young children with ASD. Its assessment questions directly correspond to hundreds of activities which can be modified for children who use augmentative or alternative communication. Basic data collection forms are also provided.

Eden Autism Services Curriculum Series

The *Eden Autism Services Curriculum Series (*2011) is a set of manuals designed for professionals, teachers, and parents using behavioral intervention with individuals with ASD. The series includes basic, key lessons for teaching skills to infants through adults, and includes manuals for teaching cognitive skills, speech and language, self-care and domestic skills, recreation and leisure, physical education, and vocational skills. The manuals provide assessments that link directly to lesson plans and grids for tracking progress in each curriculum domain. There is also an online version of this curriculum now available which automatically sets up a child's curriculum following administration of the assessment and allows for electronic data collection and graphing.

Individualized Goal Selection Curriculum

Individualized Goal Selection Curriculum (IGS; Romanczyk et al. 1996) was designed to aid in the development of behavioral intervention programs for children with severe impairments, including autism and related disorders. The IGS was created with the aim of systematizing the design, implementation, and supervision of behavioral intervention programs. Through assessment, areas of deficit are identified for each child, but they do not correspond with specific teaching activities. The IGS provides a list of 2,000 tasks addressing social, motor, language, adaptive, play, and academic skills. They are organized first by area, then by level and stage, and finally by task. The IGS does not provide lesson plans for the tasks.

Language for Learning

Language for Learning (Englemann and Osborn 1999), a revision of the Distar Language I program, uses a direct instruction approach to teach oral language skills to children 4 years of age and older. It was designed for teachers to use with children in preschool and kindergarten or in specialized primary educational settings (i.e., speech, special education, or English as a second language (ESL) classrooms). *Language for Learning* includes six different language categories: actions, object description, information and background knowledge, instructional words, classification, and problem solving. The program is implemented using group instruction and includes clear teacher scripts, assessments and placement tests, choral responding, individual turns, and error correction procedures. *Language for Learning* has been empirically validated and found to be effective for children with and without developmental disabilities (Benner et al. 2002; Waldron-Soler et al. 2002).

Making a Difference: Behavioral Intervention for Autism

Making a Difference: Behavioral Intervention for Autism (Maurice et al. 2001), a follow-up to *Behavioral Interventions for Young Children with Autism* (Maurice et al. 1996), is a collection of chapters written by professionals specializing in various areas of ASD treatment. Intended for parents, clinicians, and other professionals, the book includes chapters dedicated to describing ASD as a diagnosis, feeding problems, prompting procedures, incidental teaching, and other topics, while also serving as a curriculum guide for teaching basic-level social skills.

Rethink Autism™

Rethink Autism™ (http://www.rethinkautism.com) is an online video-based behavioral program designed for parents, teachers, and professionals to use to guide curriculum design for children and adolescents with ASD. The curriculum includes a basic library of videos addressing approximately 500 lessons and outlining step-by-step how to teach key skills in the areas of social, motor, language, play, adaptive, and academic skills. The program allows data tracking and graphing for challenging behavior, lesson acquisition, and overall progress through the curriculum. It also includes an IEP builder and a tool for conducting functional behavior assessment for challenging behavior.

Skills®

Skills® (http://www.skillsforautism.com) is a web-based program offering a comprehensive assessment that is directly linked to nearly 4,000 customizable lesson plans and a progress-tracking system. It was designed to assist clinicians, teachers, and parents conducting behavioral intervention for children and adolescents with ASD. The program includes comprehensive curricula for the eight developmental areas mentioned earlier in this chapter: social, motor, language, adaptive, play, executive functions, cognition, and academic skills. Skills® is one of the only behavioral curricula that provides ages for lesson activities and offers comprehensive programming in the areas of executive functions and cognition, starting with basic skills and advancing to highly complex skills. Skills® includes printable lesson plans, worksheets, visual aids, data sheets, corresponding IEP goals, instructional videos, data tracking for challenging behavior and important events, progress charts and reports, and an indirect functional behavioral assessment with corresponding behavior intervention plan builder (BIP) for challenging behavior. The Skills® assessment has been validated (Persicke et al., 2014) and the language subscale is reliable (Dixon, Tarbox, Najdowski, Wilke, & Granpeesheh, 2011). The BIP Builder has been shown to improve BIP quality(Tarbox, Najdowski, & Bergstrom, 2013).

Skillstreaming

Skillstreaming (Goldstein and McGinnis 1990/1997/2003) includes three books: *Skillstreaming in Early Childhood, Skillstreaming the Elementary School Child,* and *Skillstreaming the Adolescent*. All three books focus on teaching social skills to children of all populations from preschool-age through adolescence using “direct instruction principles of learning”: modeling, role-playing, feedback, and generalization. *Skillstreaming* has been empirically validated as an effective tool to increase social skills in children and adolescents with ASD (Sheridan et al. 2011; Tse et al. 2007).

The STAR™ Program: Strategies for Teaching Based on Autism Research

The STAR™ Program: Strategies for Teaching Based on Autism Research (Arick et al. 2004) is a behavioral curriculum developed for classroom intervention for school-age children with ASD. The program methodology includes discrete trial teaching (DTT), pivotal response training (PRT), and teaching functional routines. The STAR™ Program provides basic-level curricular activities focusing on six domains: receptive language, expressive language, spontaneous language, functional routines, academics, and play/social skills. The program includes an assessment linked to lesson plans and data sheets for tracking performance. A report published in 2003 (Arick et al. 2003) indicated that children receiving the STAR™ Program improved in the areas of language and social skills.

Syracuse Community-Referenced Curriculum Guide for Students with Moderate and Severe Disabilities

The *Syracuse Community-Referenced Curriculum Guide for Students with Moderate and Severe Disabilities* (Ford et al. 1989) is a handbook focused on integrating students into the public school setting and teaching them skills needed in real-life community settings. It is intended for both parents and professionals who have a basic understanding of learning principles, assessment procedures and task analysis techniques, along with a good understanding of school settings. The curriculum is based on a community-referenced guide that was originally created by the Syracuse City School District task force, which was later field tested in 12 school districts throughout the country. The guide contains a curriculum for individuals with moderate to severe impairment, ranging from kindergarten to 21 years of age. The focus is on teaching adaptive and community living skills, including leisure and play skills, self-help skills, functional academics, social communication, and motor skills. Although wide in scope, the curriculum content appears to focus on basic skills and is not comprehensive within any one domain. The authors explain that the guide was designed to provide a framework for decision making that should be applied to students on an individualized basis. It is not intended to be used as a prescribed curriculum.

Teaching Children with Autism to Mind Read: A Practical Guide for Teachers and Parents

Teaching Children With Autism to Mind-Read: A Practical Guide for Teachers and Parents (Howlin et al. 1999) was designed to provide clinicians, psychologists, educators, and caregivers with strategies for teaching children with ASD to understand mental states of themselves and others. The authors review higher-level deficits commonly observed in children with ASD, including difficulty understanding the intentions, thoughts, and beliefs of others. *Teaching Children to Mind Read* provides activities to address these deficits (e.g., recognizing and interpreting facial expressions, perspective taking, and understanding others’ beliefs).

Teaching Developmentally Disabled Children: The ME Book

Teaching Developmentally Disabled Children: The ME Book (Lovaas 1981) is one of the first instructional books for parents and professionals for teaching young children with developmental delays. It provides conceptual information related to developmental disabilities as well as intervention techniques for behavioral treatment programs. The curriculum includes lessons for teaching imitation, matching, early, intermediate and advanced language skills, early play skills, basic adaptive skills, and some academic skills.

Teaching Individuals with Developmental Delays: Basic Intervention Techniques

Teaching Individuals with Developmental Delays: Basic Intervention Techniques (Lovaas 2003) was designed as an instructional tool for caregivers acting as behavioral treatment providers for children with developmental disabilities. It is presented in seven sections: basic concepts, transition into treatment, early learning concepts, expressive language, strategies for visual learners, programmatic considerations, and organizational and legal issues. The curriculum includes lessons covering basic language, adaptive, play and academic concepts.

Teaching Language to Children with Autism or other Developmental Disabilities

Teaching Language to Children with Autism or other Developmental Disabilities (Sunderg and Partington 1998) is a teaching manual largely based on the text *Verbal Behavior* (Skinner 1957) and focuses on a functional approach to teaching language to children with ASD. It comprises four sections: assessment procedures, a curriculum for teaching language to early language learners, advanced language strategies, and implementation techniques. It includes information regarding augmentative communication and how to teach initial language skills to nonverbal children.

Teach Me Language: A Language Manual for Children with Autism, Asperger's Syndrome and Related Developmental Disorders

Teach Me Language (Freeman and Dake 1997) is a manual designed for parents and therapists for teaching language and language-based academic skills to children with ASD. The activities are suitable for children from kindergarten through teenage years who are able to communicate in some form and are compliant visual learners. It was designed based on speech pathology methods; however, the authors recommend its use in behavioral intervention settings. The manual provides step-by-step instructions, worksheets, and materials.

The Big Book of ABA Programs

The Big Book of ABA Programs (Mueller and Nkosi 2010) was designed for teachers, behavior analysts, and parents to use for the delivery of ABA-based intervention. Its over 500 activities and IEP goals are directly linked to every teachable step in the Assessment of Basic Language and Learning Skills—Revised (ABLLS®-R). It provides a comprehensive language curriculum as well as activities to teach motor, adaptive, play, social, and academic skills. It can also be purchased as part of a larger package called the *Autism Skill Acquisition Program* (ASAP™) which comes with an ABA manual, teaching materials, and an ABA graphing CD.

Think Social!

Think Social! was created by Michele Garcia Winner (2006), a Speech and Language Pathologist, in order to provide parents, clinicians, and educators with a curriculum for teaching social and social-cognitive skills. Think Social! was designed to be a curriculum for students with social cognitive deficits but verbal and nonverbal intelligence that is at least near the normal range. Thus, the population of students that could potentially benefit from this curriculum includes those with ASD, attention deficit hyperactivity disorder (ADHD), nonverbal learning disorder, Tourette Syndrome, or even head injuries. It consists of eight chapters, outlining techniques to teach observational learning, group participation, understanding and applying nonvocal cues, and self-monitoring. Lessons progress from foundational to more complex skills and are linked to IEP goals, educational standards, and social goals related to success within the school setting.

Work in Progress: Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism

Work in Progress: Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism (Leaf and McEachin 1999) is a manual designed to assist parents, teachers, paraprofessionals, and clinicians in designing behavioral intervention programs for teaching skills to children with ASD. It reviews behavioral concepts including reinforcement, behavior management, and discrete trial teaching and contains a basic curriculum and forms for tracking progress. The curriculum consists of approximately 60 skills relevant to behavioral programming for ASD, with most lessons addressing language, social, and play skills and a few lessons addressing motor, adaptive, and academic skills. *Work in Progress* stresses the importance of generalization across settings. It includes seven appendices with various forms and lists: Curriculum Assessment, Daily Data Summary, Discrete Trial Data, Overview of Programs, Performance Evaluation, Program Description, and Tracking Forms.

Conclusion

This chapter has provided a step-by-step process for linking assessment to curriculum (Table 10.1). The importance of conducting an assessment in order to identify curriculum needs for each child with ASD cannot be overlooked. Ensuring that assessment covers early child development up through the child's chronological age across every area of human functioning is equally significant. There are key traits to look for when choosing an assessment or a battery of assessments to administer. We have offered a brief review (for a full review, see Gould et al. 2011) of assessments that appear most conducive to meeting the needs of an EIBI provider and have identified which key traits each assessment possesses (Table 10.2).

Once the assessment has been conducted, there are many important factors to consider when attempting to link assessment results to lesson activities. Once these factors have been considered, the process of curriculum design begins. A number of commercially available curricula have been created to aid in the process and are available for reference when designing and customizing an individualized curriculum for each child. We have offered a review of what we believe to be the most widely used and/or useful commercially available curricula for designing EIBI programs and have outlined specific characteristics of each (Table 10.3). It is our hope that this chapter will provide helpful information for those endeavoring to link assessment to curriculum for children with ASD.

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Reinforcement Arrangements for Learners with Autism Spectrum Disorder

11

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Keywords

Reinforcement · Establishing operations · Preference assessment

Reinforcement is a process by which a consequence, a reinforcer, follows a response and increases the future likelihood of that response under similar conditions. Parents, teachers, clinicians, and other caregivers use reinforcement-based procedures in educational and therapeutic arrangements for individuals with autism spectrum disorder (ASD) to increase desirable behavior and to reduce the frequency of undesirable behavior. The precision and ultimate success of these procedures depends on selecting the right reinforcers and arranging their delivery in an effective fashion. Thus, understanding how to identify and arrange reinforcers, as well as the variables that influence the effectiveness of reinforcers, are critical to designing and implementing effective reinforcement-based interventions.

This chapter discusses research on the many factors that influence the effectiveness of reinforcement. We begin with a brief introduction to different types of reinforcers, basic reinforcement schedules, and methods commonly used to assess reinforcer efficacy. We then discuss how to identify and use reinforcers in applied settings. This section will cover types of preference assessment methods, considerations in the selection of preference assessment methods, and what stimuli to include in the assessment. We will then examine research on the stability of preferences and reinforcer value over time, factors that influence the efficacy of reinforcers, and potential solutions to changes in reinforcer value. The final section

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will focus specifically on response-reinforcer relations in persons with ASD.

Fundamentals of Reinforcement Arrangements

Again, reinforcement is a process by which a stimulus is provided contingent upon a response resulting in an increase in the future probability of the response. Reinforcement involves either the presentation of a stimulus (i.e., positive reinforcement) or the removal of a stimulus (i.e., negative reinforcement). In either case, the critical feature is that the operation results in an *increase* in the future likelihood of the response. The particular consequence that produces that increase is called a "reinforcer." In educational and therapeutic application, reinforcers take many forms including social stimuli (e.g., praise, tickles, hugs), nutritive stimuli (e.g., food and beverages), toys and activities (e.g., stuffed animals, opportunity to ride a bike or play a video game), etc. Also common is the use of conditioned reinforcers, stimuli such as points or tokens that caregivers can deliver immediately and the child can exchange later for tangible *backup reinforcers*. Reinforcers can also be categorized according to the form of stimulation they provide (e.g., visual, auditory, olfactory, tactile, nutritive, and social). There are many stimuli in an individual's environment at any point in time that serve a reinforcing function. Thus, determining the reinforcing effectiveness of a consequence is not done in isolation; rather, effectiveness is gauged in a relative sense. That is, relative to all other currently available sources of reinforcement, what proportion of behavior is allocated to a particular reinforcer. We will further consider the types of stimuli to use as reinforcers in the section on identifying and using reinforcers in applied settings.

Schedules of Reinforcement

Schedules of reinforcement dictate when and how often reinforcers are delivered. For example, behavior can be reinforced on either continuous or intermittent schedules. In a continuous reinforcement schedule (often abbreviated CRF), the reinforcer follows every targeted response. Intermittent reinforcement is far more common in natural environments and occurs when reinforcement only sometimes follows the target response. Furthermore, schedules of reinforcement can be response (ratio) and/or time (interval) based. In ratio schedules, reinforcement is provided following a prespecified number of responses. Specifically, reinforcement is provided contingent upon a set number of responses in fixed-ratio (FR) schedules and upon a number of responses that center around some mean value in variable-ratio (VR) schedules. A fixed-ratio 1 (FR 1) schedule of reinforcement is equivalent to a continuous reinforcement schedule as reinforcement is provided contingent upon each response. Interval schedules are both time and response based. During interval schedules, reinforcement is provided for the first response that follows either a fixed amount of time (fixed interval, FI) or a variable amount of time that centers around some mean time (variable interval, VI).

In nonhuman organisms, different schedules produce differing characteristic patterns of responding. For example, responding under FR schedules has been described as consisting of a rapid rate until the delivery of the reinforcer with a post-reinforcement pause (PRP) following reinforcer delivery. VR schedules, on the other hand, are associated with high and steady rates of responding with little to no observed PRP. FI schedules of reinforcement produce a scalloped pattern of responding whereby responding increases as the end of the interval approaches. VI schedules, on the other hand, produce moderate steady rates of responding. However, the educational and therapeutic contexts under which reinforcers are delivered to children with ASD rarely mimic these conditions, so those characteristic patterns may be less relevant to the current discussion. Interested readers are directed to DeLeon et al. (2013) for a fuller description of characteristic patterns and their relevance to applied settings.

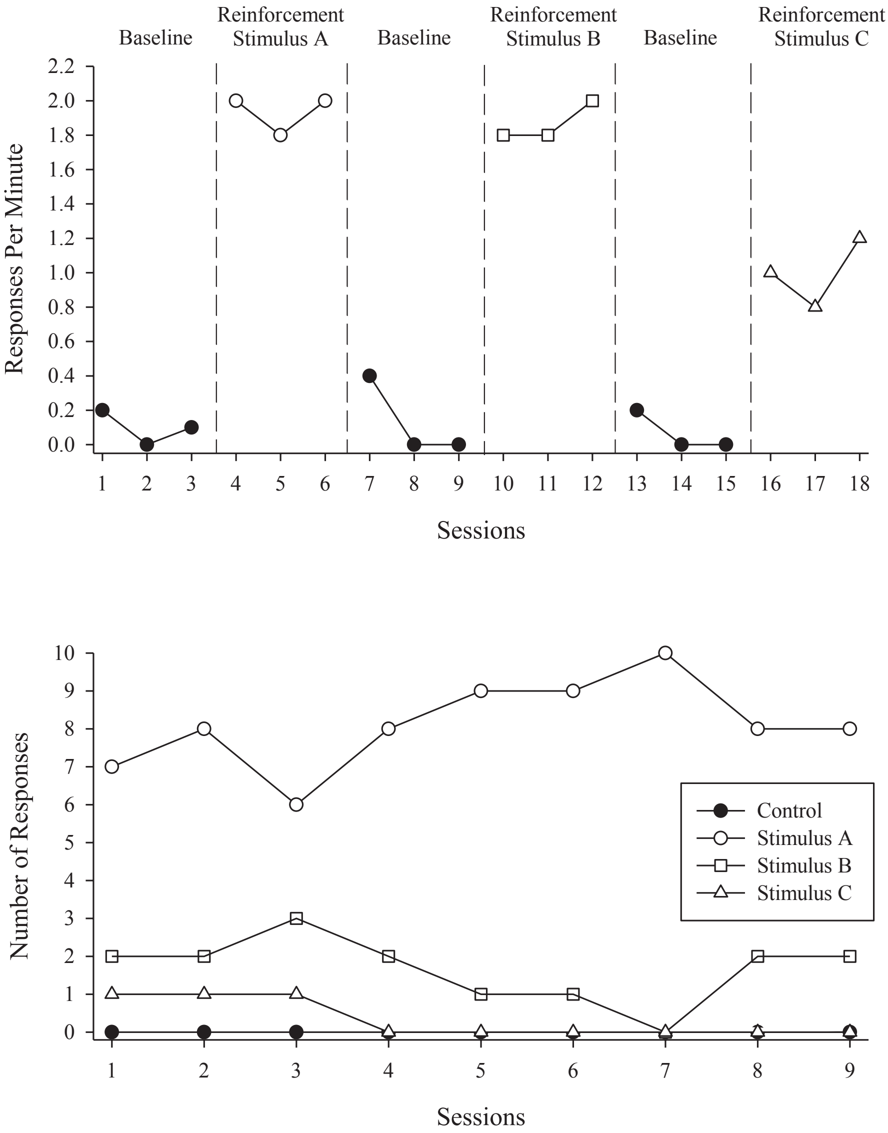

Fig. 11.1 Hypothetical data from single-operant (*top panel*) and concurrent-operant (*bottom panel*) reinforcer assessments

Methods of Assessing Reinforcer Efficacy

Behavioral researchers have used a number of different methods to assess the effectiveness of reinforcers. The most common involves a simple FR schedule; sometimes referred to as a single-operant arrangement in this context. A single reinforcement schedule is arranged for a single response and the rate or frequency of responding is used to evaluate the relative potency of reinforcers (e.g., Carr et al. 2000; Roscoe et al. 1999). Response rates during the reinforcement phase are compared to response rates during a baseline (no reinforcement) phase; reinforcers are those stimuli that increase responding relative to baseline levels. In theory, the larger the increase in responding, the more potent the reinforcer. For example, the top panel of Fig. 11.1 depicts hypothetical outcomes of this sort of preference assessment used to index the effectiveness of Stimuli A, B, and C. All three stimuli resulted in response rates that were higher than baseline, suggesting that all three are effective reinforcers. Further, Stimuli A and B produced higher response rates than Stimulus C, suggesting both are more effective than Stimulus C. However, response rate is perhaps a poor index of relative reinforcer value because variables other than the strength of the reinforcer (e.g., natural limits on the rate of responding or "ceiling effects") can have a greater influence over response rate than relative reinforcer efficacy. Thus, single FR schedules using response rate as a dependent variable may mask differences in relative reinforcer efficacy (e.g., Roscoe et al. 1999). In the top panel of Fig. 11.1, there may be real differences in the effectiveness of Stimuli A and B that cannot be detected because the individual is incapable of completing the response more quickly. Although such differences may be small, there are nonetheless conditions under which even small differences in relative reinforcer value may be clinically important.

Concurrent-schedule arrangements offer a more sensitive test of relative reinforcer effectiveness. In a concurrent-schedule, the participant can distribute responses between different options that operate simultaneously. The dependent variable of greatest interest is the distribution of responses (e.g., Piazza et al. 1996a; Roscoe et al. 1999). For example, a child may have two identical sheets of arithmetic problems placed side-by-side in front of them. Completion of problems on the right side may result in the delivery of one reinforcer according to an FR1 schedule, whereas completion of problems on the left side results in delivery of a second reinforcer on an identical schedule. All else being equal, if the child allocates more responding towards the option associated with the first reinforcer than the option associated with the second reinforcer, the first is deemed more effective. Such an outcome is depicted in the bottom panel of Fig. 11.1 where Stimulus A appears to be a more effective reinforcer than Stimuli B and C based on the amount of responding allocated to each option. Concurrent schedules may be sensitive to small differences in reinforcer value. However, it is important to note that just because a reinforcer is less preferred in a concurrent-schedule arrangement, it may nonetheless be an effective reinforcer in an absolute sense (i.e. if it was not being directly pitted against another stimulus). Although few responses were made on the Stimulus C option in the bottom panel of Fig. 11.1, suggesting it was not effective, if Stimuli A and B were not concurrently available, Stimulus C might have produced much responding, as suggested in the top panel of Fig. 11.1 (see Roscoe et al. for results very similar to this).

Applied researchers have also used progressive-ratio (PR) schedule arrangements (Hodos 1961) to assess relative reinforcer efficacy (e.g., DeLeon et al. 2009; Francisco et al. 2008; Roane et al. 2001). PR schedules are another example of a single-operant arrangement, but differ from typical single-operant arrangements with respect to how the schedule is thinned. In typical single-operant arrangements, the response requirement within a session (e.g., FR1) is typically held constant. Under a PR schedule, the response requirement increases systematically within a session (e.g., may increase in increments of 2 from FR 2 to FR 4, to FR 6, etc. within the same session). A session ends when the participant ceases to respond for some predetermined amount of time. Reinforcer value is indexed by the *breakpoint,* or the value of the last completed schedule. Thus, PR schedules provide an estimate of the amount of responding one is willing to emit towards gaining a reinforcer.

Identifying and Using Reinforcers in an Applied Setting

Preference Assessment Methods

The sorts of reinforcer assessments described above are important in validating the predictions of preference assessments. Preference assessments are methods used to identify stimuli that may function as reinforcers. Stimuli shown to be more preferred are predicted to be more effective reinforcers. Thus, a typical course in applied research on preference assessment is to conduct the assessment to determine its predictions about relative reinforcer efficacy, then test those predictions using one of the reinforcer assessment methods just described.

Behavioral researchers have evaluated numerous methods of identifying stimulus preferences. The methods vary along many dimensions, including the effort required and accuracy of outcomes. Prior to the development of these methods, clinicians relied on staff or parent report or checklists (e.g., Atkinson et al. 1984; Cautela and Kastenbaum 1967) and similar methods sometimes collectively termed indirect preference assessments. These methods are more efficient in terms of time and effort than others, but their outcomes often correspond poorly with the outcomes of more rigorous assessments (Cote et al. 2007; Windsor et al. 1994). However, there may be some benefit to conducting informal assessments to identify stimuli to include in more systematic preference assessments (e.g., Fisher et al. 1996).

Pace et al. (1985) were among the first to describe a systematic preference assessment methodology. The researchers used a single-stimulus (SS) presentation format to assess the preferences for and reinforcer efficacy of various stimuli for six individuals with intellectual and developmental disabilities (IDD). Sixteen items thought to produce different forms of stimulation were included. During each trial, one item was placed in front of the participant and approach responses (i.e., moving hand or body toward the item within 5 s of presentation) were recorded. Preference hierarchies were established by calculating the percentage of approach responses for each stimulus. During the reinforcer assessment, the reinforcer efficacy of high-preference stimuli (those approached on 80 % or greater of trials) and low-preference stimuli (items approached on 50 % or fewer of trials) was assessed. The authors found that, in general, high-preference stimuli were more likely to function as reinforcers than low-preference stimuli.

The SS preference assessment was a relatively efficient method for directly measuring the preferences of individuals with severe learning deficits. One drawback, however, was that some participants approached the majority of stimuli that were presented. This pattern of indiscriminate responding implied that all stimuli were equally preferred by some participants. Alternatively, participant learning histories and subtle demand features of the SS preference assessment may have evoked approach responding regardless of the specific item presented. Thus, SS assessments may not yield information on relative preferences, causing clinicians to select some non-preferred stimuli as reinforcers.

To address the issue of false-positive findings, Fisher et al. (1992) developed a forced-choice or paired-stimulus (PS) assessment. In this preparation, two items were simultaneously presented to the participant, who could only approach one item during each trial. This methodological variation ensured that not all stimuli would be consumed during 100 % of trials, which increased the odds of the assessment generating differentiated preference hierarchies. In a comparison of the SS and PS methods, all items determined to be high preference (selected on 80 % or greater of trials) in the PS assessment were also identified as high preference in the SS assessment. However, items classified as moderate (50–79 %) to low (50 % or below) preference in the PS assessment were also frequently classified as high-preference stimuli in the SS assessment. Thus, the PS assessment generated more differentiated preference hierarchies than the SS assessment. During subsequent reinforcer assessments, stimuli determined to be highly preferred during both types of preference assessments supported higher rates of responding than stimuli identified as highly preferred during the SS assessment but low to moderately preferred in the PS assessment. These findings suggest that the PS assessment may offer a more accurate measure of relative preference than the SS assessment.

In an attempt to develop an assessment method that required less time to implement than a PS assessment while still providing information about relative preferences, DeLeon and Iwata (1996) proposed the multiple stimuli without replacement (MSWO) assessment. At the beginning of each session, the experimenter sat across a table from a participant and placed seven stimuli in a straight line approximately 5 cm apart and 0.3 m in front of the participant. The experimenter verbally instructed the participant to approach one item. After the participant approached one item, he or she was allowed to consume or play with that item. During the next trial, the selected stimulus was removed from the array and the remaining items were again laid out in front of the participant. Trials continued in this manner until the last item was approached, or the participant did not approach any of the remaining items within 30 s. Results obtained from the MSWO were compared to those obtained from a PS preference assessment. The researchers found that PS and MSWO methods generated similar preference hierarchies, but the MSWO assessment required far fewer trials.

Although most preference assessment procedures measure approach responding to stimuli presented across a series of trials, Roane et al. (1998) developed a brief duration-based, free-operant (FO) preference assessment. The authors noted that a brief FO assessment potentially had advantages over the traditional approach-based assessments like the PS and MSWO. They suggested it was quicker to administer, allowing for more frequent assessments; stimuli were never withheld or withdrawn, which might evoke problem behavior for some individuals; and although not specifically acknowledged by the authors, the FO method allows for the assessment of larger items that cannot be presented on the tabletop. During the FO assessment, sessions were 5 min in duration. Items were placed in a circle on the tabletop, and participants were free to engage with any of the items during that 5 min. Object manipulation was measured using 10-s partial interval recording. Preference hierarchies were established by ranking items according to the percentage of intervals in which object manipulation occurred. A brief concurrent-schedule reinforcer assessment followed the preference assessment. The researchers found that highly preferred stimuli (i.e., manipulated at the highest rates) were more likely to serve as reinforcers than less-preferred items. Furthermore, when compared to results obtained from a PS assessment, it was observed that the FO assessment was less likely to generate a distinct preference hierarchy (i.e., identification of at least one high-preference stimulus and at least one relatively less-preferred stimulus). However, the FO assessment was faster to administer and was associated with less problem behavior.

Considerations in Selection of Preference Assessment Method

Behavior analysts have developed a variety of methods to identify potential reinforcers, yet recommendations regarding the conditions under which preference assessments *should* be conducted in order to gain the most informative and valid information are not readily available. Despite a lack of comprehensive information on optimizing the use of preference assessments, some studies have evaluated variables that affect preference assessment outcomes and, therefore, should be considered by clinicians and researchers whose work relates to reinforcer identification. In what follows, we consider selection of preference assessment methods, stimuli to include in the assessment, and key studies that shed light on variables impacting the validity and reliability of preference assessment results.

All direct preference assessment methods require somewhat different skills to make valid selections. Thus, to obtain valid preference hierarchies, it is important to consider prerequisite skills specific to each type of assessment in relation to the participant's current skills when selecting a method. Many preference assessments require participants to approach or interact with stimuli, thus requiring intact visual and motor skills. For example, PS and MSWO preference assessments require that an individual visually scan two or more simultaneously presented stimuli in order to make a choice and SS, PS, and MSWO preference assessments all require some type of physical (e.g., reaching for an item, leaning towards an item) or vocal (i.e., saying the name of the item) response.

The role of visual scanning has not been evaluated in the context of preference assessments. However, research on eye-tracking behavior demonstrates that, for some individuals with

ASD, selection responses made without the individual observing all stimuli resulted in impaired accuracy of delayed match-to-sample performance (Dube et al. 1999). If this were to occur in the context of a preference assessment, established preference hierarchies may not be accurate. Thus, if an individual has the ability to look at and reach or orient towards a stimulus but has difficulties visually scanning an array of items, then the SS assessment may be the most appropriate preference assessment method to use.

Even those with the ability to visually scan an array of stimuli may have difficulty with some preference assessments. Some individuals make selections controlled by location rather than by the items themselves (e.g., participants may always select the item on the left when two items are presented in the PS assessment). Eliminating positional biases can prove successful in some cases. For example, Bourret et al. (2012) were able to overcome the positional biases for three individuals by conducting training in which a choice was provided between a known non-preferred stimulus and the other stimuli used in the original PA. For two other participants, increasing the magnitude of one of the items presented along with an error correction procedure helped to overcome the bias. Although unpublished, we have had sporadic success with other methods including changing from horizontal to vertical placement of stimuli, taking one item in each hand and holding them in front of the participant, or even placing items in opposite corners of the room and having the participant walk to the selected item. Research from other areas suggests that position changes alone may only sometimes eliminate position biases (e.g., Sidman 1992). When position biases persist, it may be necessary to assess preferences using the SS or FO procedures.

Individuals with profound disabilities who do not possess prerequisite scanning and motor skills will not be able to participate in traditional preference assessments. However, the preferences of individuals with restricted motor movements may be assessed using microswitches (e.g., Datillo 1986; Gutierrez-Griep 1984; Wacker et al. 1985). Wacker et al. (1985) trained individuals with profound disabilities to emit small motor movements, such as lifting their head or raising their arm, to access various items (toys, music, etc.). Microswitches were attached to various body parts, and the number and duration of motor movements were measured. Other researchers have suggested that indices of happiness (smiling, laughing, etc.) may be differentially correlated with preferred stimuli (Green and Reid 1996). Thus, by presenting a series of stimuli and measuring behaviors that evoke the label "happiness," it may be possible to identify preferred stimuli for individuals lacking the motor skills to approach stimuli.

Clinicians may sometimes need to evaluate preferences for complex stimuli (e.g., community activities) that can be offered only through verbal or pictorial representations of the activities. A number of studies have attempted to identify the skills necessary for successful assessments of this sort (Clevenger and Graff 2005; Cohen-Almeida et al. 2000; Conyers et al. 2002). For example, Conyers et al. used the Assessment of Basic Learning Abilities test (ABLA; Kerr et al. 1977) to assess prerequisite skills for pictorial and verbal PAs. The ABLA test includes several levels, hierarchically ordered in terms of increasing difficulty. The skills assessed range from basic imitation (Level 1), to visual matching-to-sample (Level 4), to auditory match-to-sample (Level 6). Preference hierarchies generated by the tangible assessment did not match those generated by the pictorial or verbal assessments for participants who only passed up to Level 3 of the ABLA. For participants with basic visual matching skills (Level 4), preference hierarchies from the tangible assessments matched the pictorial assessment results, but not the verbal assessment. Finally, the participants who passed all visual and auditory tests generated similar preference hierarchies across pictorial, verbal, and tangible assessment methods. These data suggest that individuals must have specific matching skills in their repertoires in order for pictorial and verbal assessments to produce valid outcomes.

Several other factors should be considered in selecting a preference assessment method. For example, if time is of issue, then the FO, SS, or

MSWO preference assessments may be more appropriate than the PS assessment. As noted by Fisher et al. (1992), although the PS assessment may be an effective method to identify preferences, it takes more time to implement than the SS assessment. Furthermore, the MSWO method (DeLeon and Iwata 1996) was partially proposed as an assessment that required less time to implement than a PS assessment. DeLeon and Iwata (1996) found that PS and MSWO methods generated similar preference hierarchies, but the MSWO assessment required fewer trials and was completed in approximately half the time that it took to complete the PS assessment. Although the MSWO proved to be an effective and efficient method, fewer stimuli can be simultaneously assessed on a tabletop with the MSWO compared to what can be included in the PS assessment. Therefore, if one wishes to include a large number of stimuli and has ample time to complete the assessment, the PS assessment may be preferable.

In an analysis of the interaction between problem behavior maintained by different reinforcers and different types of preference assessments, Kang et al. (2011) found that individuals with problem behavior maintained by tangible reinforcers were likely to display problem behavior during MSWO and PS assessments, but not during the FO assessment. However, the FO assessment tended to evoke problem behavior maintained by attention. Thus, when working with individuals who engage in socially maintained problem behavior, the function of problem behavior should be taken into consideration when selecting a preference assessment method.

During preference assessments, selection responses typically result in the opportunity for a participant to consume the chosen item. Under some circumstances, it may not be practical to deliver an item immediately following a selection response (e.g., when assessing preferences for community-based items or items that cannot be presented on the tabletop). Delays between the selection response and the delivery of the corresponding item may influence the results (e.g., Groskreutz and Graff 2009; Hanley et al. 1999; Kuhn et al. 2006; Tessing et al. 2006). Hanley et al. (1999) evaluated the preferences of four individuals with severe developmental disabilities using pictures. During each assessment trial, three pictures were presented simultaneously to participants. Two pictures represented potential reinforcers and a control picture represented a presumably neutral activity. A multiple baseline design across stimulus sets was used to evaluate the effects of contingent access to stimuli on preference assessment outcomes. Two experimental conditions were included in the evaluation. In the *no access* condition, touching a picture did not produce programmed consequences. In the *access* condition, a touch response resulted in immediate access to the associated activity area for 2 min. In most cases, differentiated preference hierarchies were established only when selected items were immediately delivered following approach responses.

Similar findings have been obtained with verbal preference assessments (e.g., Kuhn et al. 2006; Tessing et al. 2006). For example, Kuhn et al. (2006) examined the role of differential outcomes on the results of verbal preference assessments with three individuals with IDD. In the verbal-plus-tangible assessment, the experimenter presented two stimuli and asked, “Would you rather have *X* or *Y*?” When the participant named one stimulus, it was available for 30 s. In the verbal-only assessment, the experimenter asked, “Would you rather have *X* or *Y*?” However, stating the name of an item did not result in access to it. The two assessments generated different preference hierarchies for all participants. During subsequent reinforcer assessments, items ranked high in the verbal-plus-tangible assessment functioned as more effective reinforcers than items ranked as highly preferred on verbal-only assessments. Results of this series of studies highlight the importance of the contingent delivery of the selected stimulus during preference assessments.

Considerations in Stimulus Selection

The previous sections have discussed different types of preference assessments and considerations in selecting a preference assessment method. Next we consider factors that may influence the types of stimuli one chooses to include in a preference assessment, and subsequently deliver in applied settings. Again, reinforcers can take many forms and some types are more commonly used than others. In a survey of the types of stimuli commonly delivered by individuals who work with persons with ASD and other special needs, Graff and Karsten (2012) found that 91.5 % of all respondents reported using social attention or praise. Tokens were used by 65.6 % of respondents, followed by breaks (65 %), edible stimuli (50.2 %), and toys (49 %). Community-based activities were least likely to be delivered (19.2 %).

When considering which types of these commonly delivered stimuli to include in a formal preference assessment, one may begin by conducting informal assessments, such as asking a caregiver to nominate highly preferred stimuli. For example, Fisher et al. (1996) sought to determine whether a structured interview form assessing caregiver nominations of preferred items would be useful in helping to construct a stimulus array for preference assessments. Six parents of children with disabilities were given a standard list of items and asked to rank order those items from most to least preferred. Parents were also provided with a carefully structured interview form called the Reinforcer Assessment for Individuals with Severe Disabilities (RAISD). The interview form instructed parents to name items they thought their child preferred in a number of categories, such as auditory stimuli, visual stimuli, edibles items, social stimuli, etc. Then, parents were asked to rank order items from the RAISD which they thought were most to least preferred for their child. PS preference assessments were conducted, and the preference hierarchies generated from the assessments were compared to parent rankings from both the standard list and RAISD assessments. The authors found that the top-ranked items identified by parent predictions based upon the RAISD were more preferred than the top-ranked items identified by parent predictions based upon a standard list of items. Thus, while caregiver reports may not consistently identify the most preferred items, they may play an important role in constructing a stimulus pool that includes the most effective reinforcers.

Although the effectiveness of a stimulus as a reinforcer is a critical consideration in arranging reinforcement contingencies, it is not the only consideration. As suggested in Fig. 11.2, another might be termed the *ecological fit* of the stimulus. By ecological fit, we refer to how well a stimulus fits into the use environment in which that stimulus will be delivered. Ideally, the stimulus used are those that fall into the upper right quadrant of Fig. 11.2, stimuli that are both effective and a good fit. A variety of characteristics of the stimulus determine how well it fits. For example, one should consider whether the stimulus is easily replenishable and relatively inexpensive, especially if one anticipates frequent delivery of the stimulus. The stimulus should be one that will remain effective for long periods of time. Duration of access to the stimulus should also be considered. If stimuli can only be delivered for short periods of time, then one may not want to include stimuli for which effectiveness hinges upon extended access (e.g., videos or games). In addition, one should ask whether it is likely to disrupt the environment or ongoing behavior. Clinicians understandably want to include the most effective reinforcers in their treatment plans. However, what is most effective may not always be the best fit for the individual’s environment. For example, community outings may motivate a student to complete his/her academic tasks and may effectively decrease problem behavior. However, they have the potential to be costly, can be difficult to arrange, and may not always be available. Similarly, provision of a movie contingent upon compliance may be disruptive to other students in the classroom. On the other hand, praise may arguably be associated with the greatest ecological fit (it is abundant and cheap, easy to deliver, is appropriate for almost any environment, and is not incredibly disruptive to ongoing behavior), but may not always be the most effective reinforcer. Therefore, it is important to balance *both* effectiveness and ecological fit.

DeLeon et al. (2013) recently created a flowchart to aid in reinforcer selection (Fig. 11.3) designed to be sensitive to this notion of ecological

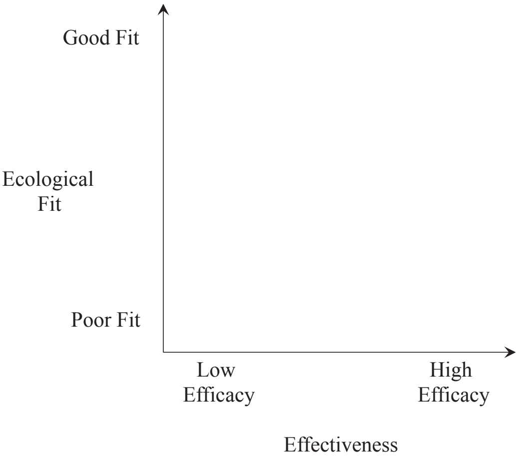

Fig. 11.2 Figure depicting the relation between ecological fit and effectiveness for reinforcer selection

fit. They suggested that one begin by evaluating the effectiveness of social consequences (e.g., praise) as reinforcers because they may have the best ecological fit. If they are effective (or can be established as effective) under simple and remain effective under more stringent conditions (e.g., under thinner schedules of reinforcement), then they should be used as reinforcers. If social consequences are ineffective, nonedible tangible stimuli should be assessed next. Although food is easily delivered, one may prefer to use nonedible tangibles for a number of reasons. For example, frequent delivery of food may be associated with mounting costs and health concerns. Furthermore, food may not be appropriate in all environments, such as in the bathroom or during some medical procedures. If nonedible tangible stimuli are ineffective reinforcers, edible stimuli should be considered last. Token systems offer a number of advantages over immediate delivery of the actual reinforcer, including not disrupting ongoing responding, mediating delays between responding and reinforcer delivery, and being less subject to satiation because they can be exchanged for a variety of back-up reinforcers. Furthermore, tokens allow for accumulated access to reinforcers. For these reasons, one may wish to assess effective nonedible and edible stimuli within token systems. If token systems are ineffective, distributed reinforcement arrangements should be used.

Although relatively little research has been conducted on the effects of different rules for constructing the pool of stimuli for preference assessments, results from several studies suggest that composition of the assessment array can influence outcomes. For example, DeLeon et al. (1997b) conducted preference assessments that included food and leisure items in the same assessment. They then repeated the preference assessment without the food and assessed whether leisure items identified as low preferred during the mixed array functioned as reinforcers. Results suggested that food items often displace leisure items in mixed arrays but, when assessed separately, those leisure items may still be effective reinforcers. This study demonstrated that simultaneously assessing stimuli from multiple stimulus classes (edible, activity, social) can influence the obtained preference value of stimuli, and, importantly, may hinder the identification of other potentially effective reinforcers. Therefore, if different classes of stimuli are to be assessed, one should conduct separate preference assessments for each class.

Duration of access to the selected stimulus should also been taken into consideration when choosing stimuli to include in the preference assessment as it has also been shown to affect preference assessment outcomes. Steinhilber and Johnson (2007) conducted two MSWO assessments of seven activities. In the MSWO-short assessment, activities were available for 15 s following each selection. In the MSWO-long assessment, activities were available for 15 min. For one participant, the assessments produced disparate hierarchies. During a subsequent concurrent-chains assessment, when items were available for 15 min in the terminal link, the items identified as high preference on the MSWO-long assessment were more preferred than the item identified as high preference on the MSWO-short assessment. In contrast, when items were available for only 15 s in the terminal link, the items identified as high preference on the MSWO-short assessment were more preferred than items identified as high preference on the MSWO-long assessment. Thus, if the duration of access to an item in a preference assessment is substantially different than

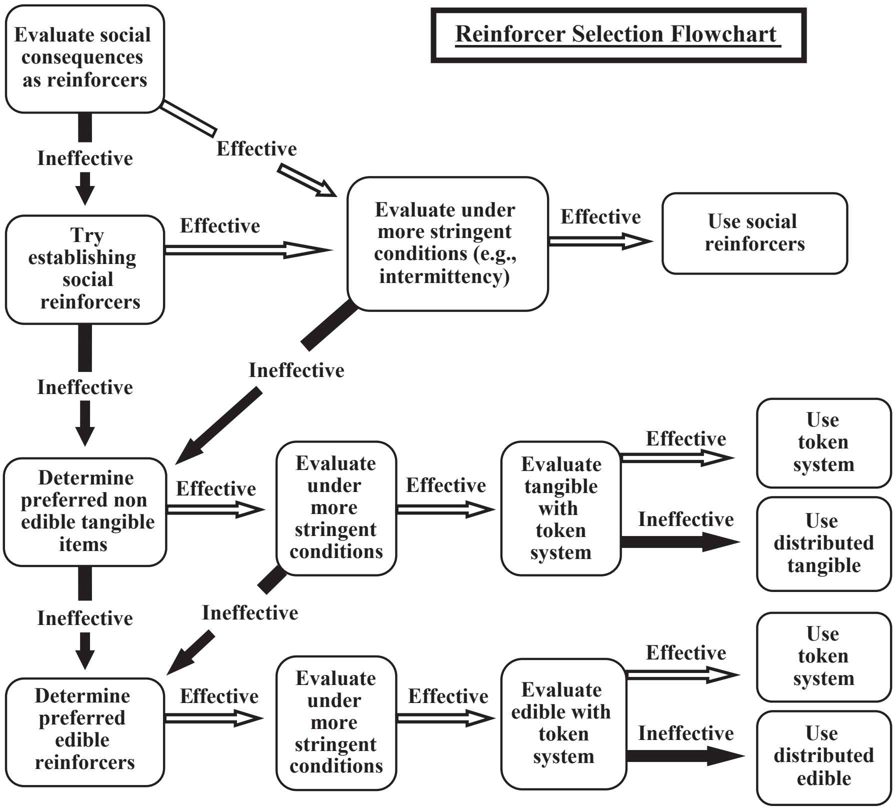

Fig. 11.3 Flowchart for reinforcer selection

the amount of time that item will be available in the natural environment, preference assessments may not identify the most effective reinforcers.

Shifts in Preference and Reinforcer Value

Variables that Influence Reinforcer Effectiveness

The effectiveness of a reinforcer can refer to both its momentary capacity to support responses that produce it and its utility in producing long-term behavior change. The difficulty in actually quantifying effectiveness lies in that reinforcer effectiveness is dynamic; it changes as a function of a number of factors. For example, Neef and colleagues have extensively examined reinforcement parameters that affect response allocation, including delay to reinforcement (e.g., Neef and Lutz 2001; Neef et al. 1993), rate of reinforcement (Mace et al. 1994; Neef and Lutz 2001), and reinforcer quality (Neef and Lutz 2001; Neef et al. 1992). All else being equal, individuals will typically allocate a greater amount of responding towards the response option associated with more immediate reinforcement, higher rates of reinforcement, and better quality reinforcers.

Delay to reinforcement The effects of delays to reinforcement have been widely studied in the context of treating problem behavior and in research on temporal discounting and self-control. For example, temporal discounting research has demonstrated that when arranged as a series of hypothetical choices between a large reinforcer delivered after some delay and a relatively smaller reinforcer delivered immediately, the current subjective value of the delayed reinforcer decreases as a function of increasing delays (e.g., Critchfield and Kollins 2001; Rachlin et al.

1991). Generally, delays to reinforcement can weaken the effectiveness of behavioral arrangements (e.g., Fisher et al. 2000; Hagopian et al. 2005; Hanley et al. 2001) and result in decreases in the value of a reinforcer (Critchfield and Kollins 2001; Rachlin et al. 1991). More recent research on discounting of primary and conditioned reinforcers has suggested that primary, directly consumable reinforcers are discounted more steeply than conditioned reinforcers (e.g., Estle et al. 2007; Odum and Rainaud 2003). It may be the case that conditioned reinforcers are less susceptible to the adverse effects of delay than are primary reinforcers and therefore maintain their value to a greater degree.

Rate of reinforcement Rate of reinforcement also affects relative response allocation. According to the matching law, an organism will distribute its behavior among concurrently available response options in the same proportion that reinforcers are distributed among those alternatives (Herrnstein 1961). In humans, the matching law has been shown to obtain in contexts that measure problem behavior (e.g., Borrero and Vollmer 2002), academic responding (e.g., Mace et al. 1994), and communicative behavior (e.g., Borrero et al., 2007).

Quality of reinforcement Quality has often been conceptualized in terms of level of preference (e.g., Hoch et al. 2002). That is, the higher the preference for a reinforcer, the better quality the reinforcer. To assess the effects of quality on reinforcer effectiveness, a number of studies have compared responding for reinforcers of varying preference (e.g., Carr et al. 2000; DeLeon et al. 2009; Francisco et al. 2008; Piazza et al. 1996; Roscoe et al. 1999). However, as noted earlier, although higher preference stimuli are often found more effective, high- and low-preference stimuli sometimes support similar rates of responding when tested in isolation (e.g., Roscoe et al. 1999). Other research assessing the *amount* of work completed for reinforcers of varying preference using PR schedules has similarly suggested that higher preference reinforcers support more work than do low or moderately preferred reinforcers (DeLeon et al. 2009). These results suggest that although low or moderate preference stimuli may function as reinforcers (particularly under conditions that may more closely resemble typical learning arrangements as in the use of single-operant arrangements), higher preference, better quality reinforcers may function as relatively more potent reinforcers.

Effort Some research on historical effort and value has attempted to assess whether the amount of work required to earn a reinforcer influences the subsequent value of that reinforcer. For example, research on "within-trial contrast" has suggested an increase in preference for stimuli that have historically followed relatively more aversive events. Clement et al. (2000) found, in pigeons, that stimuli that signaled reinforcement and were produced by more effort (20 keys pecks) were later preferred over stimuli that also signaled reinforcement, but were produced by less effort. This finding and similar others suggest a positive relation between historical effort and subsequent value—generally, stimuli produced through greater effort become valued over stimuli produced with lesser effort. Although this study did not specifically assess the effects of past effort on the current reinforcing value of the *actual reinforcer,* they do suggest that perhaps effort can enhance the effectiveness of a reinforcer. It should be noted, however, that other studies on within trial contrast have failed to replicate the results obtained by Clement et al. (e.g., Vasconcelos et al. 2007).

In an extension of this line of research, DeLeon et al. (2011b) assessed the influence of contingency and amount of effort on the preference for and reinforcing value of four reinforcers for seven individuals with IDD. In this study, moderately preferred stimuli were assigned to one of four conditions: FR1, escalating FR (increasing effort across weeks), noncontingent delivery (without any earning requirement), and restricted access. Preference and PR assessments were conducted prior to and following 4 weeks of training with each of these conditions (with the exception of the restricted access stimuli, which were stored away during the 4-week training and only presented during subsequent preference and progressive-ratio assessments). Results were mixed across participants in that contingent stimuli (i.e., FR 1 and escalating FR conditions) and those stimuli associated with greater effort (i.e., escalating FR condition) were not always associated with increases in preference or reinforcer efficacy. However, consistent across all participants was a decrease in preference for the stimuli presented without an earning requirement. Furthermore, the smallest increase in reinforcer efficacy (i.e., lowest percentage change in PR breakpoints) obtained for the stimuli in the NCR condition. These results suggest that although effort may not necessarily increase the value of stimuli as reinforcers in persons with IDD, it is possible that noncontingent delivery may devalue stimuli more rapidly.

Magnitude of reinforcement Magnitude, which can vary according to quantity, intensity, or duration (Hoch et al. 2002), is another reinforcement parameter that has been examined for its effect on reinforcer value. Although mixed results have been obtained, some studies do suggest a positive relation between magnitude and responding (e.g., Trosclair-Lasserre et al. 2008; Hoch et al. 2002). Trosclair-Lasserre et al. examined the effects of different reinforcer magnitudes on preference and reinforcer efficacy. During the preference assessment, a concurrent-operant arrangement was used to assess the participants preferences for two different reinforcer magnitudes (i.e., small vs. large or medium vs. large magnitudes) and no reinforcement. Three participants exhibited a preference for the large magnitude relative to the small magnitude and indifference between large and medium reinforcer magnitudes. For these participants, the larger reinforcer magnitude supported more responding than the smaller reinforcer magnitude ($n = 3$) and more than the medium magnitude reinforcer ($n = 2$) during a subsequent PR analysis.

Results of studies such as those conducted by Trosclair-Lasserre et al. (2008) do provide some support for the notion that reinforcer magnitude may affect the value of a reinforcer. However, other researchers have observed little effect of magnitude on responding (e.g., Lerman et al. 1999, 2002). Trosclair-Lasserre et al. suggested that the effects of magnitude on reinforcer efficacy may depend on the schedule arrangement and schedule of reinforcement used. Specifically, magnitude may affect responding under concurrent-operant (e.g., Hoch et al. 2002; Steinhilber and Johnson 2007) or PR (e.g., Trosclair-Lasserre et al. 2008) arrangements and under schedules of reinforcement associated with increased response rates, such as VR schedules (e.g., Reed 1991). Many applied studies have used response rates under single-operant schedules to evaluate the relative potency of reinforcers. However, as previously mentioned, sensitivity to relative reinforcer value may be limited by ceiling effects. Individuals may respond as fast as possible regardless of the reinforcer (or magnitude) provided. Concurrent-operant and PR arrangements are not subject to these same ceiling effects and may therefore be more sensitive to differences in the relative reinforcer value of stimuli that differ with respect to magnitude. In addition, results of studies that incorporate concurrent-operant arrangements may be more clinically relevant than those using single-operant arrangements, particularly when one considers that individuals are constantly faced with multiple response options in the real world (Trosclair-Lasserre et al. 2008).

The results of studies assessing the effects of magnitude on reinforcer value generally suggest that magnitude is an important variable to consider when it comes to reinforcer value. Furthermore, given that preference and reinforcer efficacy may vary as a function of reinforcer duration (e.g., Steinhilber and Johnson 2007), preference assessments should be conducted under conditions that more closely approximate how the reinforcer will be used in the treatment context. Lastly, magnitude may also play an important role when thinning schedules of reinforcement to make treatments more practical for use in the natural environment (e.g., Roane et al. 2007). One may wish to adjust reinforcer magnitudes as reinforcement becomes less frequent.

Continuity of reinforcer access Much of our knowledge of reinforcer effectiveness in persons with IDD is built upon distributing brief access to reinforcers following a small number of responses. However, the effectiveness of some stimuli as reinforcers may partly depend on one's ability to accumulate access to longer durations of uninterrupted reinforcement. For these stimuli (e.g., videos, games, music), procedures that interrupt continuity of access (e.g., distributing work in between reinforcer deliveries) may discount the value of the reinforcer (Hackenberg and Pietras 2000). Recent research conducted by DeLeon et al. (in press) and Fienup et al. (2011) provide evidence of the importance of continuity. DeLeon et al. assessed the efficacy of, and preference for, accumulated and distributed reinforcement. In the accumulated condition, the entire quantity of reinforcement was delivered all at once after all the work was completed. In the distributed condition, small quantities of the reinforcer were delivered more immediately after portions of the work were completed. Although the total amount of reinforcement is the same in both conditions, participants received uninterrupted access in the accumulated condition, but after a greater delay inherent in requiring that all the work be completed first. During Experiment 1, results of a reinforcer assessment suggested that accumulated access to reinforcers resulted in rates of responding that matched or exceeded those obtained when reinforcement was distributed. In Experiment 2, all participants preferred to accumulate access to activities. Similarly, Fienup et al. (2011) observed that one participant preferred a reinforcement arrangement that required that all work be completed prior to accessing the reinforcer (i.e., fluent work) to one in which the reinforcers were distributed throughout the work period (i.e., disfluent work). Results of both studies suggest that continuity, whether it be in terms of reinforcer access or how work is arranged, can influence the effectiveness of reinforcement arrangements.

Motivating operations Motivating operations (MOs) are environmental events, operations, or stimulus conditions that serve a reinforcer establishing function (i.e., momentary alters the reinforcing effectiveness of other events) and an evocative function (i.e., momentarily alters the frequency of occurrence of the type of behaviors that produced those other events as a consequence). By definition, MOs affect the value of reinforcers. Two commonly studied MOs include satiation and deprivation. With stimulus deprivation, the reinforcing effectiveness of the stimulus and the frequency of behavior that produce the stimulus as a consequence momentarily increase. During satiation, the reinforcing effectiveness of the stimulus momentarily decreases as does the frequency of behaviors that have produced that stimulus as a consequence.

Satiation and deprivation can influence preference rank (e.g., Gottschalk et al. 2000; McAdam et al. 2005) and impact the effectiveness of common reinforcers. For example, Vollmer and Iwata (1991) examined rates of simple responses under conditions of deprivation and satiation for food, activities, and attention. States of deprivation resulted in relatively higher rates of responding than did states of satiation and during baseline for all but one participant (i.e., activity for Donny). Satiation resulted in a decrease in responding relative to baseline for activity reinforcers and for one participant for food. Zhou et al. (2002) extended this line of research by assessing deprivation and satiation for food reinforcers under less contrived arrangements (i.e., assessing deprivation by conducting sessions 30 min before lunch and satiation by conducting sessions 30 min after lunch). Results revealed higher rates of premeal responding for four of nine participants. Thus, it appears as if MOs can influence preference for stimuli and *may* influence reinforcer value, but perhaps less so under naturalistic conditions.

Concurrently available stimuli and behavioral economics With the exception of studies on quality of reinforcement, much of the research discussed thus far has incorporated identical reinforcers to assess the effects of variables such as delay, effort, magnitude, continuity, and MOs. More recently, concepts and principles used to characterize consumption of a commodity in a microeconomic system have been incorporated into behavior analysis to similarly characterize the effectiveness of a reinforcer when other, qualitatively different reinforcers are available. This area of research is known as behavioral economics (Kagel and Winkler 1972; Hursh 1980, 1984). The application of behavioral economic principles to the study of human behavior offers the advantage of allowing researchers to investigate choice under conditions of asymmetrical reinforcers and under various conditions of constraint.

From a behavior economic perspective, an individual's behavior is considered a form of currency that is "spent" to obtain commodities (i.e., reinforcers). An individual has a finite amount of behavior to spend and, as with money, the purchase of one reinforcer often occurs at the expense of another. The "unit-price" of a reinforcer (the behavioral cost or price incurred to produce a reinforcer divided by its magnitude) has been shown to vary inversely with consumption. Simply stated, as the price of a commodity increases, consumption of that commodity decreases (the *Law of Demand*).

The degree to which changes in price affect consumption will vary according to the commodities under consideration. *Elasticity of demand* describes the extent to which changes in unit price influence consumption of the commodity. Demand for some commodities may be more sensitive to changes in price while demand for others may be less sensitive. A demand function illustrates how much of a given commodity an individual will consume over a range of unit prices (Hursh 1980). Demand is described as being inelastic when changes in price produce less than proportional changes in consumption. Demand is considered elastic when changes in price produce larger than proportional changes in consumption.

A number of variables have been shown to influence elasticity of demand, including the nature and price of alternative stimuli and the economic system in which consumption and responding take place. The economic concept of substitutability has been used to describe a continuum of possible interactions among concurrently available reinforcers, with reinforcers that compete with one another on one end of the continuum (i.e., substitutes), those that are typically consumed together on the other end of the continuum (i.e., complements), and those that are independent of one another falling in the middle (i.e., independents, Green and Freed 1998). When consumption of a commodity is highly sensitive to changes in its price or the availability and price of another commodity, the available alternative is said to be highly substitutable for the first. Substitutable reinforcers have been described as stimuli that are functionally similar (Green and Freed 1993, 1998; Madden 2000). Although little research has directly examined the relation between the degree of functional similarity and substitutability, some research does *suggest* that functionally similar reinforcers are more substitutable (e.g., DeLeon et al. 1997a; Johnson and Bickel 2003). For example, DeLeon et al. (1997a) used progressively increasing, concurrent FR schedules in persons with IDD to determine whether preferences between two reinforcers changed as the schedule requirements (i.e., the number of responses per reinforcer) for both reinforcers increased. When two dissimilar reinforcers were concurrently available (e.g., a small edible item and a toy), no clear preference for one item over the other was observed, regardless of the FR schedules in effect. By contrast, when the concurrently available stimuli were functionally similar (e.g., two food items), a clear preference for one item emerged as the schedule requirements were increased. DeLeon et al. (1997a) suggested that this effect may have been attributable to the greater degree of substitutability between functionally similar reinforcers versus functionally dissimilar reinforcers. Furthermore, the authors suggested that increased schedule requirements may magnify small differences in relative preference between similar stimuli to a greater extent than dissimilar stimuli, perhaps because similar stimuli that share physical characteristics (e.g., two food items) are more likely to share functional properties as well (e.g., hunger reduction). More research is certainly needed in this area but these results do provide some preliminary evidence to suggest that the effectiveness of a reinforcer may decrease if a functionally similar, substitutable reinforcer is concurrently available at a cheaper price.

The economic notion of open and closed economies (Hursh 1980, 1984) also seems relevant to reinforcer effectiveness in persons with

IDD. In an open economy, total daily consumption of a reinforcer is not dependent on responding because supplemental access to the reinforcer is provided. However, no supplemental access to the reinforcer is provided in a closed economy—the entire quantity of the reinforcer must be "purchased." As a result of the supplemental access provided in the open economy, less responding to produce the reinforcer is supported under open economic conditions (e.g., Hall and Lattal 1990; Hursh 1980). Although the majority of research on open and closed economies has focused on nonhuman animals as subjects, there are a number of implications for clinical populations, specifically for the development of reinforcement-based programs. For example, Roane et al. (2005) evaluated the effects of open and closed economies on completion of academic tasks for two children with IDD. During both economic conditions, the response requirements increased within session according to PR schedules. Higher levels of task completion were observed under the closed economy. These results are consistent with findings from basic research and suggest that the efficacy of a reinforcer may be altered if supplemental access to that reinforcer is available outside the context in which the reinforcer is earned.

Accommodating Shifts in Preference and Value

Stimuli previously demonstrated to be highly preferred are sometimes incorporated into treatment packages without regard to when the preference assessment was conducted. This is troublesome because preferences, and hence reinforcer effectiveness, can change over time. Zhou et al. (2001) examined rank-order correlations for leisure items during PS preference assessments conducted between 12 and 20 months apart. The mean rank-order correlation obtained equaled 0.11 for the entire array of stimuli assessed, although when only the top five ranked stimuli were considered, greater stability was observed. Other researchers examining shifts in preference for edible stimuli specifically have observed greater stability (e.g., 0.46 after 12 months; Ciccone et al. 2007). These results suggest that while preference does shift, it may be most stable for the highest-ranking items and that stability may vary across stimulus classes.

Importantly, shifts in preference have also translated into changes in the utility of reinforcers. DeLeon et al. (2001) conducted a PS preference assessment at the beginning of their study. Daily MSWO preference assessments were then conducted using the same items from the PS assessment. On days in which the top-ranked item from the PS and MSWO assessments differed, reinforcer assessments were conducted using the top-ranked item from the initial PS assessment and from that day's MSWO assessment. During the concurrent-operant assessment, participants typically allocated more responding to the option associated with the top ranked item identified during the MSWO. This outcome suggests the shifts in preference are associated with corresponding shifts in reinforcer effectiveness.

Clinicians have assessed a number of methods to address changes in preference and in reinforcer value. For example, as demonstrated by the study conducted by DeLeon et al. (2001), conducting frequent, brief preference assessments may enhance performance by accommodating momentary fluctuations in stimulus preference. Several other methods exist for incorporating different reinforcers into treatment arrangements and varying reinforcers to accommodate preference shifts. One such method is stimulus variation. Rather than repeatedly presenting the same reinforcer, stimulus variation arranges for the rotation of different reinforcers following responding. Stimulus variation can increase response rate and decrease interresponse time (Egel 1980, 1981). Furthermore, the varied presentation format may be preferred to the presentation of a constant stimulus even if the varied reinforcers are of lesser preference but still somewhat preferred (Bowman et al. 1997). However, this effect has not always obtained for *non-preferred* varied stimuli (Koehler et al. 2005). Thus, stimulus variation appears to have some effect on preference and even responding but only in so far as the stimuli that are being presented are moderately to highly preferred.

Another method commonly used to incorporate different stimuli is the provision of reinforcer choice. Choice can be arranged as a presession selection in which the individual chooses the reinforcer they would like to earn in the following instructional session or within-session (or post-response) selection in which the individual chooses from a small array of reinforcers contingent upon meeting the schedule requirements. Research comparing preference and reinforcing efficacy of these two arrangements has shown that individuals seem to prefer the within-session choice and they may even respond at higher rates when choices are presented within session as opposed to prior to session (Graff and Libby 1999). However, research examining whether choice increases responding relative to when no choice is provided has tended to demonstrate little to no effect regardless of whether choice is provided prior to session (e.g., Smith et al. 1995) or during session (e.g., Lerman et al. 1997). Although choice has not always proven beneficial, individuals do seem to prefer the opportunity to choose their reinforcers over no opportunity to choose (Geckeler et al. 2000; Tiger et al. 2006), even if the reinforcers they are choosing among are identical to one another (Tiger et al. 2006).

Response-Reinforcer Relations in Persons with ASD

Identifying potent reinforcers is extremely important, as effective reinforcers are a central part of early intensive behavioral intervention and individualized education plans. ASD is characterized by impairments or excesses in certain domains (e.g., social communication, restricted interests, and repetitive behavior) that may have some bearing on how reinforcers are selected and arranged specifically for learners with ASD. These considerations include preference or aversion to social stimuli, potential deficits in abilities to engage in social play, and restricted interests and repetitive behavior. In general, different levels of disability are found in individuals diagnosed with ASD, and the number of behavioral characteristics that make up this developmental disorder can be quite heterogeneous. Therefore, we will speak broadly about how different behavioral characteristics may affect reinforcer sensitivity and create idiosyncratic relations between responding and reinforcers; however, these considerations may be important for some individuals but not others and may also apply to individuals without an ASD diagnosis.

Social Interaction

One of the core diagnostic features of ASD includes impairments in social communication. This may naturally lead some to believe that individuals with ASD do not like social stimuli or that such stimuli do not function as effective reinforcers for persons with ASD. In fact, some researchers have hypothesized that individuals with ASD may experience a deficient responsiveness or lack sensitivity to social stimuli as reinforcers (e.g., Dawson et al. 2001; Dawson et al. 2002). This lack of sensitivity may directly lead to some of the qualitative impairments in social interactions observed in individuals with ASD.

Impaired social communication presents a number of problems for persons with ASD. For example, given that so many learning experiences are mediated though social interactions, deficits in social behavior may exert profound effects on other domains of functioning (e.g., social-emotional and language development; Mastrangelo 2009). Furthermore, the failure to engage in, and hence derive reinforcement from, social interactions may have direct implications for the use of reinforcers for individuals diagnosed with ASD. Specifically, individuals who do not engage in social interaction may be less motivated to obtain access to group activities and social attention in general, which may be particularly problematic when providing praise as a reinforcer. Above we suggested the use of praise as a reinforcer whenever possible because praise may be more natural, less intrusive, and obviates satiation effects. However, the differences in social development for individuals diagnosed with ASD may make praise an ineffective reinforcer or may require extensive training to establish praise as a reinforcer.

Deficits in social behavior, and their implications for development, have led some to directly examine preferences for social stimuli and whether social stimuli function as reinforcers for persons with ASD. Results of research on preference for social stimuli among persons with ASD have been somewhat mixed. Some research suggests a preference for contexts devoid of social interaction (e.g., Celani 2002). Others have shown that children with ASD may simply exhibit indifference towards various types of social interactions (Call et al. 2013). Others still have shown that teachers can readily identify at least one form of social interaction that is an effective reinforcer for a learner with ASD (Smaby et al. 2007). From our perspective, the principal message is that it is a dangerous assumption that children with ASD will not find social interactions reinforcing. As in all cases of determining reinforcer effectiveness, there are great individual differences across learners.

In relation, a number of studies have suggested that some individuals with ASD may find social interaction aversive and that such interactions may even occasion problem behavior (e.g., Hagopian et al. 2001; Taylor et al. 1994). Other studies examining the role of attention in the maintenance of problem behavior have compared outcomes of functional assessments for persons with and without ASD (e.g., Dawson et al. 1998; DeLeon et al. 2011a; Reese et al. 2005). Results have generally suggested that individuals with ASD are less likely to have problem behavior maintained by access to attention than individuals without ASD. However, differences between groups were small in some cases (e.g., 31.8 % in the ASD group and 40.5 % in the non-ASD group; DeLeon et al. 2011a). In each of these studies, some percentage of individuals with ASD *did in fact* exhibit problem behavior to access adult attention, again suggesting that attention can function as a reinforcer for persons with ASD.

Given all the advantages associated with delivering social stimuli as reinforcers (e.g., low cost, ease of use, not interrupting ongoing behavior), one may wish to try to establish attention as a reinforcer if it does not already function as one. A number of researchers have attempted to establish attention as a reinforcer for individuals with a wide range of intellectual and developmental disabilities (e.g., Dozier et al. 2012). In general, two pairing procedures have been used to establish social attention as a reinforcer: noncontingent and contingent pairing procedures. In the noncontingent pairing procedure, primary reinforcers (e.g., food) are delivered freely and attention is consistently provided during food consumption. In the contingent pairing procedure, primary reinforcers and attention are simultaneously provided contingent on the completion of a task. Following either pairing procedure, the effectiveness of the attention in the absence of food is measured through task completion. In a direct comparison of these procedures, research has suggested that the noncontingent pairing procedure has proven ineffective. The contingent pairing procedure has proven effective in establishing attention as a reinforcer, but in less than 50 % of cases (Dozier et al. 2012). Therefore, procedures to enhance the contingent pairing procedure should be assessed. In addition, only one individual in the Dozier et al. (2012) study was diagnosed with ASD, thus additional research is needed on the robustness of this finding among persons with ASD.

Restricted Interests and Repetitive Behavior

Another diagnostic criteria of ASD is the presence of restricted interest or repetitive behavior. It is possible that a lack of interest in more developmentally appropriate play is directly related to insensitivity to social contingencies. That is, without the presence of appropriate peer models for behavior, stereotyped interests and behaviors may be more likely to occur and contact nonsocial reinforcement (Wolfberg and Schuler 1993).

Restricted interests and repetitive behavior may make identifying reinforcers for persons with ASD difficult for several reasons. First, restricted interests can result in a limited field of stimuli to draw upon for inclusion in preference assessments. Second, individuals who engage in stereotypic responses to the exclusion of other types of play will have likely developed few play skills, further reducing the types of stimuli that one can evaluate. The individual may also prefer the repetitive behavior to almost anything else, impeding the identification of other, more appropriate, reinforcers. Finally, from a practical standpoint, stereotypic behavior may interrupt assessment procedures by competing with selections during preference assessments or responding during reinforcer assessments.

When the continual occurrence of repetitive behavior makes procedures to assess reinforcers difficult, the best course of action may be to evaluate the effects of reinforcers in a free-operant format such as with a competing items assessment. A competing items assessment examines the degree to which access to various items displace aberrant behavior, such as repetitive behavior, relative to a control condition where no potential competing items are included. If the repetitive behavior decreases, the item competes with repetitive behavior. If the repetitive behavior increases, the item complements the repetitive behavior. A number of studies have demonstrated that noncontingent access to competing items can effectively reduce stereotypic behavior maintained by automatic reinforcement (e.g., Piazza et al. 1996b; Ringdahl et al. 1997; Shore et al. 1997).

In some cases of extremely restricted interests, one of the most potent reinforcers may be access to the stereotypic response itself (Hanley et al. 2000). Although restricting and then providing contingent access to repetitive behaviors may be an effective way to teach new skills, caregivers may object to the provision of access to stereotypic responses because of the social stigma associated with some stereotypy. Furthermore, some may fear that contingent access to repetitive behavior may in fact make it appear as if one encourages or condones stereotypic responses. However, Potter et al. (2013) recently found that teachers who worked with individuals who received this type of treatment thought the treatment was highly acceptable and would recommend for other therapists.

With respect to restricted interests, one promising approach is to teach variability in play routines that already occur. Procedures to enhance response variation have been shown effective in studies to increase traditional play skills (e.g., Goetz and Baer 1973), variability in verbal responding (e.g., Lee et al. 2002) and computer play skills (e.g., Miller and Neuringer 2000) for persons with ASD. Lee et al. 2002, for example, increased variation in verbal responding in individuals with ASD by reinforcing verbal responses only if they differed from the previous verbal response. Results of studies on response variation, particularly those conducted with persons with ASD, suggest that when stereotyped behaviors or interests exist, the addition of differential reinforcement may be an effective means to increase response variation.

Best Practices and Recommendations

As noted earlier, Graff and Karsten (2012) recently surveyed over 400 educators and clinicians regarding their practices for reinforcer identification. Only slightly more than half reported using any form of direct preference assessment method, and many respondents reported a lack of knowledge or time as a barrier to systematically determining effective reinforcers for learners with ASD and other special needs. Seemingly, much remains to be done towards educating caregivers responsible for these learning arrangements about making effective use of reinforcement systems. The current chapter has proposed a number of person and environment-specific factors one should consider to aid in the planning of reinforcement systems. We conclude with a summary of what we believe, based on the evidence discussed above, to be best practices for learners with ASD.

First, we presented only a handful of the preference assessment methods available to caregivers, but those presented are the ones most common in the behavior analytic literature. Based on this literature, we offer the following recommendations regarding which method to use for specific learners.

1. If the individual has the requisite visual scanning and motor skills, PS assessment should be used if time permits, MSWO if time is limited.
2. If motor skills are intact but the individual cannot visually scan an array of stimuli, the SS assessment may be most appropriate.
3. For individuals with position biases, the SS or FO assessments should be considered if training to overcome the position bias proves ineffective.

4. For persons who lack the ability to visually scan an array and who have limited motor control, the use of technology (e.g., microswitches) or indices of happiness could prove useful in aiding in the identification of preferred stimuli.
5. Complex stimuli can be assessed through the use of pictorial or verbal preference assessments if the individual has the requisite identity matching skills (visual MTS for the pictorial assessment and auditory MTS for the verbal assessment).
6. If the individual engages in problem behavior maintained by access to preferred stimuli, the FO assessment should be considered. If the problem behavior is maintained by attention, one should use the PS, SS, or MSWO assessment.
7. When possible, always try to provide access to the selected stimulus.
8. When identifying the items to be included in the preference assessment, one should consider both the ecological fit and likely effectiveness.
9. Separate preference assessments should be conducted for different classes of stimuli.

It is important to note that preference assessment results are just predictions of stimuli that will likely function as reinforcers. Preference assessments are often conducted under very low response requirements or using simplistic schedules. For example, many types of assessments simply require that the participants reach for or state the name of the stimulus (e.g., PS or MSWO), whereas others only require that the individuals engage with the item (i.e., FO). Stimuli identified as highly preferred under these simplistic conditions may not always function as reinforcers under conditions that more closely parallel actual training contexts (e.g., using actual work or realistic schedules of reinforcement). Therefore, it is important to validate predictions made by preference assessments using reinforcer assessments.

It is also important to remember that preferences and the reinforcing value of stimuli may change over time. Furthermore, MOs can alter preference for and the value of stimuli. Continuity may be of particular importance for certain classes of stimuli, such as activities. To address some issues associated with shifts in preference and reinforcer value, one could consider conducting frequent preference assessments, varying stimuli in treatment arrangements, or providing a choice of potential reinforcers. Finally, although a number of diagnostic features of the disorder can impede the identification of reinforcers for persons with ASD, we wish to reemphasize that caregivers should not simply assume that social stimuli would not function as effective reinforcers for children with ASD.

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Discrete Trial Teaching and Discrimination Training

12

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Keywords
Discrete trial training · Prompting · Discrimination

Discrete trial teaching (DTT) and discrimination training are among the most supported components of early and intensive behavioral intervention (EIBI). DTT is a highly structured procedure for presenting learning opportunities to the child, and discrimination training concerns how these opportunities are structured to optimize learning. This chapter starts with a description of the elements of DTT, followed by a brief description of other teaching procedures often used in conjunction with DTT. Subsequently, we describe the areas in which DTT has been applied and the scientific support it has received. In the next section, we provide a detailed description of the most common discrimination training procedures, together with other more systematic and incremental procedures used when the more traditional approaches have been unsuccessful. In the last section of this chapter, we discuss other strategies and procedures that can be used to optimize and individualize DTT and discrimination learning.

Discrete Trial Teaching

Background

Discrete Trial Teaching (DTT) is a behavior analytic procedure designed to improve the developmental and educational outcomes of individuals with autism and other developmental delays (Smith 2001). Although DTT was developed in the 1960s (Green 2001), it is still a chief component of contemporary early and intensive behavioral intervention (EIBI) programs (Eikeseth 2011).

The purpose of DTT is to help individuals to learn skills that have not been acquired spontaneously, or have not been learned from regular education or special education. Hence, DTT has *not* been designed to help individuals with a specific psychiatric diagnosis such as autism. Also, DTT has *not* been designed specifically for children. It can be used to teach individuals of any age who benefit from a highly structured teaching environment when learning new skills. For a comprehensive overview of how DTT can be used in primary and secondary schools, see Smith (2012).

Most individuals with developmental delays have a history of failed attempts in teaching situations. Typically, parents and teachers will try to teach children skills they perceive that the child has failed to learn spontaneously. Although

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laudable, this also means that children have experienced frustration from failure and from tasks that are too demanding. DTT is a specific type of one-to-one, teacher–child directed instruction that individualizes, simplifies, and structures teaching in a specific way to maximize learning. This is done in several ways:

Firstly, learning targets are carefully matched in difficulty to the child's current level of functioning. The targets selected for teaching are operationally defined and judged to be relatively easy for the child to acquire. As the child acquires these targets, they are either combined with other acquired targets into more complex tasks or the complexity of the targets is gradually increased in a stepwise manner.

Secondly, a technique known as *prompting* is used. Prompting is a specific type of help provided by the teacher to guide the child to correctly perform the target response. Prompts can be anything from physically guiding the child to the target response (e.g., taking the hands of the child and putting them together for the child to clap) to modeling a correct verbal response to a question ("What color is a tomato? Say 'Red'"). Over successive presentations of the learning task, the teacher gradually makes the prompt less and less salient, so that the child eventually responds correctly to the task without any prompt. Such prompting techniques result in a high degree of error-free learning, which by itself makes it easier for the child to learn the tasks. In addition, learning with few errors may keep the child's motivation high.

Thirdly, DTT involves the systematic use of consequences and the systematic repetition of tasks until particular targets are mastered. The consequences provided for correct answers are any item or activity that is likely to be a positive reinforcer for that child, such as praise, happy faces, stickers, brief access to favorite toys, blowing bubbles, a small piece of a favorite food, listening to music, or watching YouTube films for a minute or two.

Components of Discrete Trial Teaching

DTT consists of five main elements. What follows is a description of each of these elements, beginning with the trial.

Trial DTT consists of a series of *trials,* each lasting for approximately 5–15 s. Each trial starts with the teacher presenting the child with a task (the *Antecedent Stimulus)*. If it is unlikely that the child will respond correctly, presenting the task is followed immediately with an additional stimulus, the prompt, designed to help the child to perform the target response correctly. For example, if the task is color identification, the prompt might be that the teacher points to the red stimulus card on the table after saying "Give me red." Immediately after the child has responded, the teacher provides the child with feedback on his/her response. In the case of a correct response, the teacher immediately provides the child a *reinforcer* (S^R). The reinforcer may be praise, brief access to a favorite toy, a game or an activity, a token, or something to eat or drink. The reinforcer is typically available for only 3 to 10 s (in the case of food or drink it should be consumed within a few seconds) so that the next trial can be started. If the child responds incorrectly, the consequence could be nothing at all, or verbal feedback communicating that the response was incorrect (such as teacher saying "Try again," "Almost," or "Nice try") (Smith et al. 2006).

One of the chief benefits of DTT is that the trials can be kept short and simple, and be frequently repeated in a highly systematic way. Up to 10–15 trials are presented per minute. Ideally, the child works on a particular target (e.g., color identification) in blocks of 2–5 min, and subsequently, the child is given a 2–3 min play break. After this play break, the child restarts DTT for 2 to 5 min, typically on a different target (e.g., answering Wh-questions). This is again followed by a brief play break and another DTT session. These DTT sessions (i.e., DTT interspersed with play breaks) last no less than 10–15 min and usually do not exceed 1–2 h. Whether the DTT sessions last for 10 min or 2 h depends on the age of the child and what type of skills the child needs to learn. Trials on a particular target are repeated until the child produces the target response correctly and without prompts for 80–90 % of the time the task is presented to the child.

Between the DTT sessions, the child and the teacher typically leave the teaching room and participate in play, leisure activities, or natural environment teaching (see chapter on naturalistic teaching strategies in this volume). If the child is in a preschool or kindergarten, the child can participate in play, educational, or social activities with other children in the class between the DTT sessions. Sessions of DTT might be repeated several times during the day, as some children may do up to 3–6 h per day of DTT. Typically, the child works on up to 12 different targets (programs) during DTT sessions, and interventionists rotate between the different programs by, for example, starting a new program after each play break. Frequently rotating between different programs likely helps keep the child motivated.

Before starting DTT, the teacher should:

1.	Organize the teaching room so there are no unnecessary distractions for the child
2.	Organize the teaching room so it is comfortable for the child and for the teacher
3.	Know the exact goal for each program
4.	Know exactly which instructions to give to the child
5.	Know exactly what constitutes a correct response
6.	Know exactly what teaching materials to use
7.	Have teaching materials ready, well organized and within the teacher's reach
8.	Select a number of reinforcers to use during teaching and have them within reach

Antecedent Stimulus (the Task) Each trial starts with the presentation of the antecedent stimulus. The antecedent stimulus consists of the interventionist presenting an instruction and some sort of task to the child. For example, the teacher shows the child a car and asks "What is it?" The question and the car together constitute the antecedent stimulus, and this antecedent stimulus is meant to evoke a particular answer from the child. The antecedent stimulus need not include a verbal question; it can be any situation which the child needs to respond to, such as seeing some other children playing a game (then the response could be to ask to join) or seeing some crayons and paper (for which the response could be to draw).

For each exercise, the antecedent stimulus is always carefully defined and it should be explicitly written as a part of the child's program description. Moreover, if stimulus cards are used, sometimes it is helpful to write the instruction that the teacher is supposed to give to the child on the back of each stimulus card. For example, if teaching the child to name colors, the teacher shows the child a blue color card, and asks, "What color?" The instruction "What color?" could be written on the back of the color card so that the teacher remembers to say, "What color?" instead of, for example, "What color is the card?" or "What color do you think this is?"

When presenting an antecedent stimulus, the teacher should:

1.	Simplify the language used as the instruction to match it to the child's language level. For example, for early learners, "Car" or "Give me car," instead of "Can you give me the car?" or "Do you know which one is the car?"
2.	Present tasks that are appropriate for the child's skill level (i.e., ensure prerequisite skills are already in place)
3.	Use a natural, friendly, and clear voice
4.	Use the exact type of stimulus material and wording that has been decided for the particular task being taught
5.	Give the child 3–5 s to respond before any consequences are given
6.	Present the instruction only once within each trial

Prompt The purpose of the prompt is to help the child produce the correct response after the antecedent stimulus has been presented (MacDuff et al. 2001). For example, the teacher might say "Clap," and then manually guide the child's hands to produce a clap. This is known as a physical prompt. If the antecedent stimulus is a question requiring a verbal answer, the teacher could model the correct answer so that the child can imitate it. For example, the teacher would present a doll and ask, "What is this?" and a verbal prompt would be to say "Say doll" immediately after saying "What is this?" Obviously, this prompt requires that the child is already able to imitate speech. Other types of prompts include pointing prompts (e.g., pointing to the object car after saying "Touch car"), position or proximity prompts (e.g., putting the car closer to the child than the other stimuli), time delay (e.g., across trials gradually delaying the onset of the prompt after providing the S^D, with the hope that the child might produce the correct response before the prompt is given), and modeling prompts (e.g., the teacher shows the child the correct response).

All prompts must eventually be faded so that the target response is produced by the antecedent stimulus only. For example, initially the teacher might manually guide the child to clap, but then over successive trials the teacher can let go of the child's hands earlier and earlier until the child can clap independently. Such fading of prompts is one of the cornerstones of effective DTT.

When prompting the teacher should:

1. Provide the prompt as specified in the teaching program, which typically means that the prompt is presented immediately after the S^D. However, other strategies for prompting can be used, such as presenting the prompt together with the S^D or gradually, over successive trials, increasing the time between the S^D and the prompt
2. Use the least intrusive prompt necessary to produce the correct response
3. If a particular prompt is not effective, use a more intrusive prompt in the next trial
4. Refrain from using non-intentional prompts such as always looking at the correct stimulus, orally mimicking the correct verbal response, or always leaving the correct stimulus in the same place, etc.

Response It is important to remember that responses are meaningful *only* in combination with a specific antecedent stimulus. For example, it would be pointless to teach a child to simply clap randomly in all situations. What is important, however, is that the child can clap as a response to other children clapping or when someone is asking him/her to clap.

The target response is always defined in observable behavioral terms, as precisely as possible, and written down as part of the child's program description. During DTT, the child's response can be:

a. Correct: A correct response *without* prompt occurs within 3–5 s of the presentation of the antecedent stimulus.
b. Prompted: A correct response *with* prompt occurs within 3–5 s of the presentation of the antecedent stimulus.
c. Incorrect: The child's response does not meet the criteria required in the response definition, or it occurs more than 5 s after the presentation of the antecedent stimulus.
d. No response: The child does not respond to the antecedent stimulus in any particular way. This can be due, for example, to lack of motivation or lack of attention. No response does not necessarily indicate that the child cannot perform the task.

The teacher should:

1. Allow the child 3–5 s to respond
2. Observe if the response is correct, incorrect, prompted, or if it is a no response
3. Refrain from repeating the instructions or talking about other things while waiting for the child to respond

Reinforcer, S^R (the Consequence) To increase the likelihood that the child will produce the target response given the specified antecedent stimulus, responses are differentially reinforced. This means that the child is presented with a desired item or activity as quickly as possible after the target correct response has been performed. Reinforcers can be verbal praise, tickling, favorite toys, games, or snacks. Which stimuli function as reinforcers depends on the child's interests, and hence may vary greatly across children. Some children may like to watch YouTube movies while others prefer bouncing on the trampoline. Moreover, the extent to which a particular stimulus functions as a reinforcer also depends on motivational variables such as deprivation and satiation. Therefore, which stimuli function as reinforcers for each child will vary from time to time. For example, if the child has not played with bubbles for a while (deprivation), blowing bubbles might be highly reinforcing. However, after blowing bubbles a number of times (satiation), bubbles might temporarily lose their reinforcing properties until the child has again not seen the bubbles for a while.

There are a number of different ways to identify reinforcers for a particular child, such as (a) asking the parent and teachers what the child likes to do (e.g., Fisher et al. 1996); (b) observing what the child is playing with or doing when he/she participates in an unstructured activity; and (c) letting the child sample different items, by, for example, presenting various items to the child and observing which items he/she chooses (Roane et al. 1998; Cote et al. 2007). An ideal procedure is to provide the student with an opportunity to make a physical choice between two or more reinforcers at the beginning of each block of trials and to use the chosen stimulus as the reinforcer for that block of trials.

Sometimes reinforcement needs to be given when the child produces approximations of the target response. This is called *shaping* and is a technique from behavior analysis that teaches the child the target response by reinforcing successive approximations to it. For example, if the child is learning vocal imitation of the sound "Ah," then initially any kind of vocalization on the part of the child is reinforced. Gradually, over successive trials, only vocal sounds are reinforced, and when the child reliably emits vocal sounds during 80–90 % of the trials when the discriminative stimulus (S^D) "Ah" is presented, only those sounds that approximate the sound "Ah" are reinforced. Finally, only the sound "Ah" is reinforced, and this continues until the child emits the sound "Ah" during 80–90 % of the trials where the S^D "Ah" is presented.

Social stimuli such as a smile and praise are almost always a powerful reinforcer for the behavior of typically developing children. One of the characteristics of children with autism spectrum disorder (ASD) is that many such social stimuli do not function as reinforcers, and this probably affects their learning and development in a negative way. To establish (or strengthen) social stimuli as reinforcers for the behavior of children with ASD, the presentation of tangible reinforcers (e.g., favorite toys, snacks, or activities) is always paired with the presentation of social stimuli such as verbal praise (e.g., "Good job!") and smiles. The rationale is that social stimuli alone will eventually become reinforcing through a process called *classical conditioning*.

To avoid the child satiating on reinforcers and losing his/her motivation for learning, it is important that the teacher identifies a number of different reinforcers for each individual child, and that the teacher presents different reinforcers on successive trials (i.e., the teacher varies the way he/she praises the child across trials and the teacher uses different tangible reinforcers across successive trials). In addition, it is important to save the stimuli that are likely to be the strongest reinforcers for when the student performs a particularly difficult task.

Another way to avoid satiation can be to use a token economy system. In a token economy, correct responses produce tokens. Tokens can be check marks, stickers or happy faces, and the like. Whenever the child has collected a set number of tokens (e.g., ten tokens) the child can exchange the tokens for a backup reinforcer. The backup reinforcer must be a very potent reinforcer, such as watching a video for a few minutes, eating a favorite snack, or playing a favorite game.

It is important to note that behaviors taught in DTT are of little use if the child does not use them outside of the DTT setting. During DTT, the behaviors are usually maintained by arbitrary reinforcers; that is, by reinforcers that are not related to the behavior being taught (e.g., the child is reinforced with small bites of a cracker for playing with a doll in a specific way). Moreover, in DTT these reinforcers are typically delivered at a high frequency. This type of reinforcement is not provided in natural settings, and hence, the child may fail to perform newly learned skills in everyday life if specific measures are not taken to ensure generalization and maintenance.

To help the child transfer skills learned in DTT to natural settings, the teacher can:

a. Reduce the frequency of artificial reinforcers used in DTT after the child has begun mastering a particular skill.
b. Observe whether or not a particular behavior learned in DTT is maintained by natural reinforcers in natural settings. For example, if the other children in the preschool play a particular game

and the child in treatment finds interaction with peers reinforcing, then playing that particular game after learning it in DTT will likely be naturally reinforced by the other children.

c. Whenever a behavior learned in DTT is *not* performed or maintained in the natural settings, the teacher must design a system for presenting the artificial reinforcer, at least for a while, to ensure that the behavior is performed and maintained in this setting. Often, a token economy system is used for this purpose, where the child receives tokens for performing specific behaviors in the natural setting. These tokens can later be exchanged with favorite activities such as playing a computer game, etc.

For more thorough discussions of reinforcement, see the chapter dedicated to variables that impact reinforcer effectiveness and for a thorough discussion of teaching and generalizing skills in the natural environment, see the chapter dedicated to natural environment training in this volume.

When using reinforcers (S^R) the teacher should:

1. Present the S^R as quickly as possible after the correct response occurs
2. Observe the child to see whether he/she is "enjoying" the S^R, as indicated by consuming and/or interacting with it. If not, alternative reinforcers should be considered
3. Pair tangible S^R with social stimuli such as praise and smile
4. Vary the tangible S^R across trials
5. Vary the social S^R across trials

Generalization After the child has learned a particular skill, generalization occurs when the child uses the new skill in a somewhat different way than the way it was taught. For example, generalization has occurred if the child names all dogs that he or she meets as "Dog" and not the specific examples of dogs that were used during teaching. If the child does not generalize, which is often the case, then generalization must be explicitly taught. This is done by expanding, one by one, the examples of dogs that function as antecedent stimuli for saying "Dog," until the child generalizes to all dogs. This procedure is called multiple exemplar training or "training sufficient exemplars" (see chapter on teaching cognitive skills in this volume). When the student is able to exhibit the skill in the presence of untrained stimuli (e.g., new examples of dogs that were never taught), it is called stimulus generalization. In addition, the child must learn to generalize across settings (or situations). That is, the child must learn to use the word "Dog" outside the teaching room, such as in other rooms and places in the preschool, at home, at the playground, in the car, etc. Moreover, the child must also use the label "Dog" when with other teachers, with parents and siblings, and with other children, which is called generalization across people. Finally, the child must be able to maintain (remember) the skill over time, and this often requires the skill to be occasionally rehearsed (e.g., once a week or once a month).

It is particularly important to address generalization when using DTT. Although DTT is highly effective in teaching new skills, the particular structure of this teaching procedure differs in many ways to how the child learns and behaves in real life settings. These differences may challenge generalization, and hence the teacher must not assume that the child will automatically perform new skills learned in DTT in other places and with other people. It is possible that the child will learn a number of new skills in the one-to-one setting with a particular teacher in the room where the teaching takes place, but subsequently fail to use these skills at home, with parents or siblings, playing with other children or even with other preschool teachers. With careful planning and monitoring of generalization, the child can learn to respond adequately to the full range of naturally occurring situations.

When using DTT, generalization should be addressed by:

1. Assessing whether the child can perform the new skill when exposing him/her to other materials found in daily life (e.g., different pictures or different objects of an item learned)
2. Assessing whether the child can perform the new skill in new places (e.g., home, playground, other places in the preschool, etc.)
3. Assessing whether the child can perform the new skill for other adults (e.g., different teachers and parents)
4. Assessing whether the child can perform the new skill for other children
5. Assessing whether the child can maintain the skill over time

Other Teaching Procedures Often Used in Conjunction with DTT

In addition to DTT, children typically participate in other types of instructional or play activities, performed in groups or individually, depending on the child's needs. Since the skills learned in DTT are initiated by the teacher, DTT has been criticized for making the child passive and teacher dependent, resulting in generalization difficulties and lack of spontaneity. This criticism is valid in the sense that DTT is not the most effective way to teach all type of skills. For that and other reasons, two other behavior analytic teaching procedures called incidental teaching and natural environment teaching are often used in conjunction with DTT. Virtually all contemporary comprehensive EIBI programs for children with autism implement a combination of DTT and naturalistic behavioral teaching strategies (see chapter on naturalistic teaching strategies in this volume for a thorough treatment of the topic).

Areas of Application and Scientific Support

Many intervention packages for children with developmental delays, especially autism, include DTT together with other behavior analytic techniques (Eikeseth 2009). Much of the support for DTT is indirect in the sense that those programs that have received much research interest and have been shown to be highly effective in teaching children language skills and adaptive behaviors (Reichow 2011) have used DTT alongside other techniques. An example of this is EIBI, which was pioneered by Dr. O. Ivar Lovaas (Lovaas 1987, 2003). A recent meta-analysis analyzing nine peer reviewed, controlled outcome studies on EIBI, found a large effect size (1.10) for change in IQ scores and a moderate effect size (0.66) for change in adaptive behavior scores (Eldevik et al. 2009).

Although these findings are based solely on children with autism, there are indications that EIBI including DTT might be effective for children with intellectual disabilities (Eldevik et al. 2010), and for children with severe intellectual disabilities and pervasive developmental disorders (Smith et al. 1997).

Intensity of DTT There is an extensive and ongoing debate about what constitutes the optimal intensity of DTT. Most likely, the optimal intensity or amount of DTT for a particular child will depend on several factors, including the child's level of functioning. Children with little or no language or who lack basic skills such as motor or vocal imitation need more DTT than children who need to learn more subtle social skills such as peer interaction. Having said this, it should be noted that intervention programs that have included a large portion of DTT combined with other one-to-one behavior analytic teaching procedures have yielded the largest effects (Eldevik et al. 2010).

Imitation One of the skill areas most commonly and successfully taught using DTT is imitation (e.g., Coe et al. 1990; Lovaas et al. 1966, 1967; Young et al. 1994). This entails gross motor imitation (e.g., clapping when someone else claps), fine motor imitation (e.g., copying a sign-language sign), vocal imitation of phonemes (e.g., repeating consonant-vowel combinations), words and phrases (e.g., repeating novel words and sentences), as well as imitation of complex play skills (e.g., playing like other children). Imitation is gradually made more difficult by moving, for example, from clapping to imitating various play behaviors, such as filling a car with gas. Imitation skills in each area (such as gross and fine motor imitation) are taught until the child achieves generalized imitation (i.e., the child imitates novel movements or sounds on the first attempt without prior practice on that specific imitation). Imitation is not only useful in natural settings, such as when learning new words and behaviors from peers and adults, but is also used as an effective prompt in other DTT exercises.

Language DTT can be used to teach both receptive and expressive language (also see chapter on verbal behavior in this volume). Receptive language includes responding to and the comprehension of verbal instructions (Lovaas 2003). Examples of this could be to point to different objects when they are named, or following instructions such as "Clap" or "Jump." Receptive language is usually built up from simple discriminations such as these to more complex instructions such as "Get the big red ball from the living room." The effectiveness of using DTT to teach receptive language has been shown in multiple studies on a wide range of language skills (Lovaas 1977; Risley et al. 1972).

There is often a need to teach the child to *use* words, even if he/she can understand them when they are spoken by someone else. Expressive language is the production of verbal statements, such as naming objects or answering questions. As with receptive language, expressive language is first taught at a simple level and is then made gradually more difficult, up to telling stories, asking questions, or engaging in small talk (McGee et al. 1984). DTT can also be used to teach children grammar. For instance, the child can be taught to correctly use plurals (Baer et al. 1972), grammatical tense, pronouns (Lovaas 1977), adjectives (Risley et al. 1972), and answering Wh-questions (Jahr 2001). It should be noted that all the techniques that are used to teach children spoken language can just as easily be used to teach sign language (Carr 1979).

Vocal imitation is a necessary prerequisite to teaching expressive language, as this is frequently used as a prompt to help the child produce the target verbal response (Baer et al. 1972; Risely et al. 1972). As with receptive language, many studies have shown the effectiveness of using DTT to teach expressive language (Lovaas 1977; Howlin 1981).

Play skills Teaching children play skills is often an area of high priority. Enabling a child to play is important because it makes social interaction with peers both easier and more rewarding for the child, and it also decreases time spent in stereotypic behaviors (Lovaas 2003). Children with autism very often lack basic skills for cooperating with peers, but this may be taught (Downs and Smith 2004). Play skills are taught like any other skills, by presenting the child with an antecedent stimulus (usually the play materials) and prompting a target response. When presenting the child with a new game or new play material, this novel activity is usually not rewarding to the child by itself, and it is important that the teacher uses reinforcers when teaching the child the play behaviors. Eventually, some play activities may become intrinsically reinforcing to the child and are thus maintained without the use of other types of reinforcers.

Most play activities require a large number of independently taught responses, both verbal and nonverbal. Playing with dolls can be broken down into a number of smaller responses such as dressing, feeding, and talking with the doll (and countless more). The child is taught each of these responses separately through prompting and differential reinforcement. Subsequently, they are chained together so that, for example, putting on one sock is an S^D for putting on the other sock, which in turn is the S^D for putting on the dress, etc.

The type of play skills usually taught initially includes playing with cars, trains, and dolls, doing insert and jigsaw puzzles, lotto, drawing, and ball games. It is important to include typically developing peers in the play activity as quickly as possible after the child has learned to perform the play activity with the teacher. The child must also be taught how to initiate play with other children, comment on what their peers are doing, and take on different roles in pretend play.

Two studies have reported on the effectiveness of teaching children play using DTT alone. Coe et al. (1990) reported successful teaching of a simple ball game to three children with autism or Down's syndrome. Jahr et al. (2000) taught cooperative play to six children with autism, all of whom mastered cooperative pretend play and generalized to novel settings and peers.

Daily living skills Another high priority in DTT programs is to teach the child age appropriate self-help skills (also see chapter on independent living skills in this volume). As with play, these skills can be broken down into component behaviors which are taught independently and subsequently chained together to form a particular self-help skill. Common daily living skills that can be taught with DTT include: using utensils, drinking from a cup, dressing and undressing, and washing hands. As in the play exercises described above, the child is presented with an antecedent stimulus in the form of a situation requiring action or an instruction. The child is then prompted, verbally, manually, or by modeling, to perform the target behavior. The prompts are slowly faded until the child responds correctly without help. Some daily living skills may become automatically reinforcing and maintain themselves (such as undressing to go to bed and listen to a story), while others (such as cleaning one's room) often require continued reinforcement from a teacher or parent.

Matson et al. (1990) taught a number of different self-help skills (tying shoes, brushing teeth, combing hair, putting on pants, shirt, and socks, and eating and drinking) to four children with mental retardation, three of whom also had autism. A majority of the skills were successfully mastered by the children and maintained at follow up several months later. The authors note that mastering the complete sequence of skills most likely helps maintain the sequence because of naturally occurring positive consequences (i.e., tying shoes to go outside to play).

Reducing stereotypic and problem behaviors Many children with developmental delays exhibit stereotypic and maladaptive behaviors, sometimes dangerous to themselves or to peers. DTT may concomitantly decrease problem behaviors in the child, by both strengthening incompatible behaviors and by making teaching situations highly rewarding (Dib and Sturmey 2007). In addition to this, DTT aims to increase communicative skills in children, which in turn might decrease problem behaviors by giving the child more adaptive alternatives to tantrums or problem behaviors to get what he/she wants (Matson et al. 1996; Smith 2001).

Other curriculum skills DTT must be combined with an appropriate and comprehensive curriculum for the child to make maximum gains. The content of the curriculum is comprehensive and addresses all areas of deficit and must be individually tailored for each child's needs. The key components of the curriculum are described elsewhere (Leaf and McEachin 1999; Lovaas 1977, 2003; Lovaas et al. 1981; Maurice et al. 1996, 2001; chapter on linking curriculum to assessment in this volume), and are only summarized below.

Beginning curriculum Each child's curriculum is individualized and comprehensive, teaching skills in all areas of development. Beginning skills included prerequisites in the areas of attention, communication, social initiations, and play. Examples include sitting in a chair, responding to simple instructions such as "come here" and "wave bye-bye," requesting favorite items, pointing, joint attention, matching identical objects, imitating gross motor actions or imitating actions with objects, imitating sounds and words, identifying and naming objects, playing independently with toys, and basic interactive skills such as rolling a ball to and from an adult.

Intermediate curriculum Intermediate skills include further language training such as identification and naming of abstract concepts, parallel play, turn taking, imitating sentences, early academic skills such as identifying letters and numbers, drawing imitation and tracing, and self-help skills such as dressing and undressing, toilet training, drinking from an open cup, and increasing the range of food and drink taken.

Advanced curriculum Once these skills are acquired, more advanced skills are addressed, such as conversation and asking questions, advanced pretend play and cooperative play, social-emotional skills such as theory of mind and perspective taking, advanced academic skills, self-management and self-control skills, observational learning, and learning in the classroom environment.

Alternatives to DTT DTT differs from another commonly used behavior-analytic technique known as pivotal response training (Koegel &

Koegel 2006). DTT stresses the need to build a complete behavioral repertoire in a systematic and incremental manner, behavior by behavior, while pivotal response training aims to identify and teach key (pivotal) behaviors which are assumed to automatically lead to spontaneous learning. Pivotal response training is designed as an alternative to DTT and hopes to achieve similar results with less intervention (Koegel & Koegel 2006).

Pivotal response training differs from DTT in that it is less structured, both in regard to where the training takes place and what is being taught. Pivotal response training is more dependent on initiations from the child in natural settings. This takes advantage of the momentary motivation of the child (e.g. wanting a cookie or a specific toy) and teaching a relevant response in that situation (e.g., "Say 'cookie'!") (Delprato 2001). However, pivotal response training can most likely neither achieve the same number of repetitions for any particular response as DTT, nor teach discriminations that are hard to master for a particular child (see discrimination training below).

Reviewing studies comparing DTT to other normalized and less structured interventions, Delprato (2001) reported larger gains for children who received more informal behavior analytic interventions. It is likely that different teaching techniques are differentially effective for different children (Schreibman et al. 2011). For example, DTT is likely to be more efficient for teaching basic learning skills (such as generalized motor and vocal imitation) and discriminations. Normalized interventions are likely to be more efficient for teaching generalized language use and to expand a basic behavioral repertoire that may have to be taught using DTT (Smith 2001). However, it is worth noting that, to date, no comprehensive outcomes studies have been published on EIBI programs that make exclusive use of naturalistic teaching strategies. Put another way, every single published controlled outcome study evaluating EIBI has contained a large proportion of DTT, usually combined with some amount of incidental teaching and/or natural environment training.

Discrimination Training

Discrimination training is an important element of DTT. Discrimination training is concerned with the way training stimuli and prompts are presented, and how prompts are subsequently removed. For example, if the child has learned to name a red block "Red," and a blue block "Blue," the child has learned to discriminate the colors red and blue, and the procedure used to establish this discrimination is called discrimination training.

What constitutes the optimal procedure for discrimination training may vary across children. Moreover, it may vary within the same child depending on which skills are being taught. Some skills are complex to learn and hence may require an elaborate discrimination training procedure involving many steps and a high number of training trials, whereas other skills are easier for the child to learn and might be effectively taught in considerably fewer trials. The teacher must always seek to use the discrimination training procedure which leads to mastery most quickly, and, typically, the more complicated and elaborate discrimination training procedure used, the more trials it takes to complete. We will start with a description of the most basic discrimination training procedure.

Basic Procedure: Teaching Language Comprehension

The following description of discrimination training is illustrated with a receptive language program, which is designed to teach the child to select particular objects (or pictures) upon hearing the name of the objects. This program is commonly known as receptive labels (Lovaas 2003), or manded stimulus selection (Michael 1985). Table 12.1 provides a summary of the teaching stages outlined below.

Mass Trials of the first Target without Distracters Mass trialing without distracters is the first step of this procedure. The aim is to teach

Table 12.1 Each teaching stage during discrimination training is shown, together with a summary of the process that is worked on in each stage

Teaching stage	Process during teaching stage
Mass trials S1	Mass prompting S1, 9 out of 10 correct
	Mass trials S1 + 1 ND, 9 out of 10 correct
	Mass trials S1 + 2 ND, 9 out of 10 correct
Mass trials S2	Mass prompting S2, 9 out of 10 correct
	Mass trials S2 + 1 ND, 9 out of 10 correct
	Mass trials S2 + 2 ND, 9 out of 10 correct
Block rotation S1 and S2	S2 + S1 as D, 9 out of 10 correct
	S1 + S2 as D, 9 out of 10 correct
	S2 + S1 as D, 3 out of 3 correct
	S1 + S2 as D, 3 out of 3 correct
	S2 + S1 as D, 2 out of 2 correct
	S1 + S2 as D, 2 out of 2 correct
	S2 + S1 as D, 1 out of 1 correct
	S1 + S2 as D, 1 out of 1 correct
Random rotation S1 and S2	Random presentation of S1 and S2

S1 stimulus one (e.g., car), *S2* stimulus two (e.g., dinosaur), *ND* neutral distracter, *D* distracter (e.g., dinosaur or car)

the child to select an object when given an instruction to do so. The selection response can be pointing, touching, or giving the object to the teacher. Often, giving the object to the teacher is a good selection response because the response requires the child to have more contact with the object as compared to when the response is only pointing to or touching, however no published research has definitively shown that one modality is superior to the others.

The child sits at the table (usually opposite the teacher) with no other training stimuli on the table except the object that is being taught (e.g., a car). If the child has no history of reinforcement for selecting the car at this stage, the likelihood that the child will correctly select the car contingent on hearing its name is low. Therefore, the teacher gives the child the name of the object vocally and then immediately following (or simultaneously) gives the child a prompt to perform the correct response. Following the completion of the correct response, reinforcement is delivered. Fading the prompts can be done very quickly for some children. Teachers can sometimes use a hand over hand prompt or simply point to the stimulus (i.e., the car) for the first few trials and then completely remove the prompts altogether. For other children, the process of fading the prompts may take longer and may need to be performed across many more trials, and very systematically across the members of the team teaching the child. In the latter case, it is still very important that prompts are faded as quickly as possible because it is sometimes the case that children with autism will become dependent on the prompts and will learn to wait for the prompt before making any attempt to perform the response independently.

Following the withdrawal of the prompts, the child is then able to perform the correct response independently. At this stage, the target object is still the only object on the table, and the child has most likely not learned to recognize the receptive noun car. For example, if the teacher said “San Francisco” to the child, instead of “Car,” the child would most likely give the car to the teacher. Hence, more steps are needed to teach the child to correctly discriminate the car. The next step is to present other objects on the table (in addition to the target object) as distracters, while asking the child to give us the car.

Mass Trials of the first Target with Distracters This step teaches the child to select a particular object (i.e., the car) and not any other object upon the teacher’s request. The teacher places the car and one other object on the table, equidistant from the child, in a line across the middle of the table. The distracter is a neutral stimulus (neutral distracter, ND) because it has not been used previously for teaching, and because it is not an object of particular interest for the child. The teacher requests the target object, and because the child now has a history of reinforcement for touching the target object, many children will require only a small prompt (if at all) to select the correct object. The teacher continues to work on the child selecting the car in the presence of the ND, and works on randomly presenting the two objects on the table in different positions (left or right) until the child is able to select the correct object for 90 % of trials.

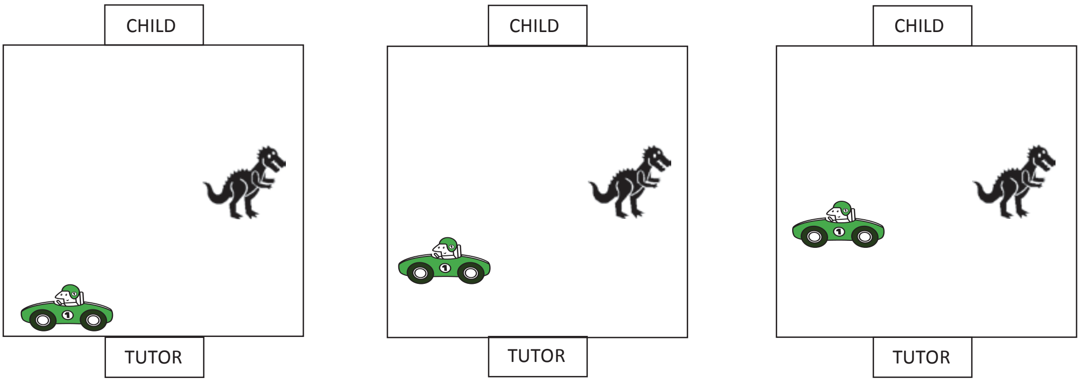
Next, a second ND can be added into the field of objects on the table. In a field of two objects (the car and the ND), the child has a 50 % chance of selecting the correct object just by guessing, and therefore to be certain that the child is able to visually discriminate the target object from other objects, we introduce a third object into the array on the table. The second ND can be selected as the first one was, and introduced into the field of objects using the above prompting procedures, if required. The teacher continues to ask only for the car, but the position of the three objects on the table can be changed at random. The child must be able to select the target object correctly in 90 % of trials before moving to the next stage of teaching. At this stage, the child has learned to select a particular object when given an instruction to do so, but the child has most likely not yet learned the receptive label car. That is, no matter if we say "Car" or "San Francisco" the child will most likely select the car.

Mass Trials of the second Target While maintenance trials are done for the car, teaching the second target noun label (e.g., dinosaur) begins and proceeds in the same way as described above (i.e., mass trials first alone, then with one and then two NDs). The reason we have selected the label dinosaur is that it contrasts well with the car. This is because the word "Dinosaur" sounds different to the word "Car" (in that it contains different sounds and the words are of different length), the objects look different from each other, and they have nothing in common.

The teaching trials for the second object (dinosaur) should *not* be done immediately before or after the maintenance trials for the first object (car) in the same session for some children because of carry-over effects. At the end of the teaching for the object dinosaur, the child should be able to correctly select the object dinosaur when the teacher says "dinosaur" for 90 % of consecutive trials, and with the dinosaur in the presence of two NDs, and when all three objects can be placed in random positions on the table. The same is true for the first object taught (car), but as yet the two objects have not been placed on the table at the same time, and the teacher has not presented the names "car" and "dinosaur" in consecutive or random trials.

Block rotation The aim of block rotation (also referred to as "expanded trials") is to have the two target objects that were previously worked on separately on the table at the same time, so that while hearing the name of target object one, the child selects that object, and when hearing the name of target object two, the child selects object two. This can be difficult for some children at first because the child has been reinforced for selecting both objects in the past, and up to now, there has been no focus on distinguishing between (discriminating) them. Now the child has to discriminate or listen to the object's name in order to produce a correct response. At this stage of discrimination training the child must learn to attend more closely to the verbal label given by the teacher because the choice of object is governed by the verbal label that is heard by the child. Figure 12.1 illustrates the following procedures.

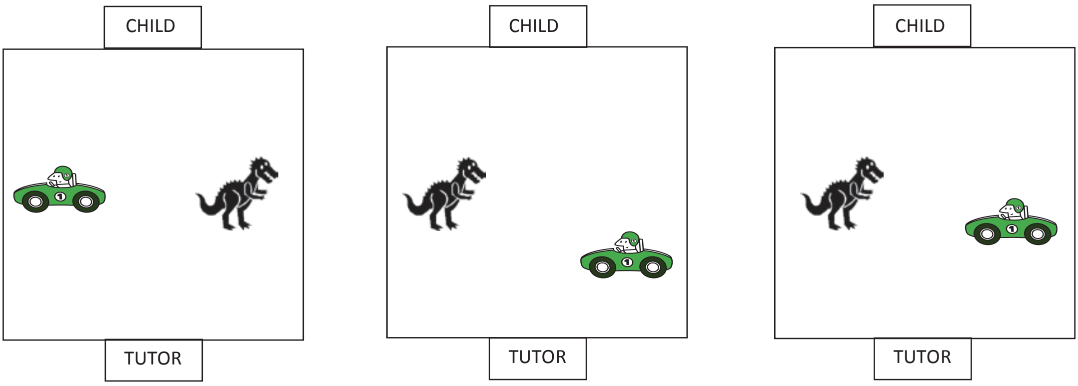
The teacher should continue to work on the second stimulus (in our example, dinosaur) because this is the one that has been worked on most recently and therefore the child is more likely to select this stimulus. The teacher places the stimulus (dinosaur) in the middle of the table but this time also places the first stimulus (car) on the table simultaneously. The car is placed at the back of the table, nearest the teacher, and the position of the stimuli makes it more likely that the child will select the stimulus in the middle of the table due to the lower response effort involved. Positioning the second stimulus at the back of the table and furthest away from the child is



(1) Full position prompt

(2) Half position prompt

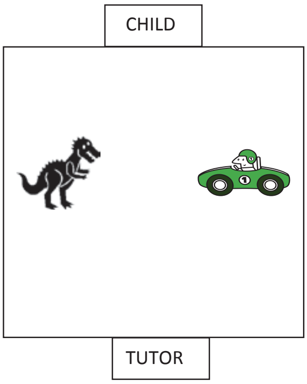
(3) Quarter position prompt



(4) No position prompt

(5) Switch position, half position prompt

(6) Quarter position prompt



(7) No position prompt

Fig. 12.1 To show the progression of the position prompts from full position prompt to no position prompt during block rotation known as a *position prompt*. The teacher says the label ("Dinosaur") and the child selects the correct stimulus. Across repeated trials, the teacher moves the first stimulus (car) gradually forward on the table so that it is eventually in line with the dinosaur, and after mastery of this step, the left-right position of the two objects is randomized across trials. In other words, the position of the two objects is switched, and if needed position prompts can be used by moving the first stimulus (car) back on the table (nearer the teacher). This procedure is repeated until the child is able to select the second stimulus (dinosaur) in either the left or right position on the table with the first stimulus (car) level each time the positions are switched and with no position prompting used, on 90 % of consecutive trials.

When the child is able to do this, the teacher then works on the same procedure but this time when saying the verbal label for the first stimulus taught ("Car"). Because the child now has an extended reinforcement history for selecting the second stimulus (dinosaur), it is more likely that the child will touch that stimulus in the presence of any verbal noun given by the teacher. Therefore, when the teacher begins work on the first stimulus, the same procedure of using position prompts described above is used again, but this time with the first stimulus placed in the middle of the table and the second stimulus placed at the back of the table. The same procedures are used during this stage, and the child will get to the stage where they have learned to select the first stimulus (car) in either the left or right position on the table with the second stimulus (dinosaur) level each time the positions are switched and with no position prompting used.

Throughout this stage, the teacher has been presenting the child with blocks of trials for each stimulus being taught. The next step is to systematically reduce the number of trials in each block for each stimulus. For example, the teacher might present the verbal stimulus "Car" until the child responds correctly for three consecutive trials with the position of the car and the dinosaur randomized. Following the third correct trial of "Car" the teacher might switch to presenting the verbal stimulus "Dinosaur" while keeping the position of the car and the dinosaur on the table the same as in the previous trial. Upon a correct response, the position of the car and the dinosaur on the table is again randomized, and whenever the child responds correctly for three consecutive trials, the teacher might again switch to presenting the verbal stimulus "Car."

When the child is able to do three consecutive trials correct after making only two to three errors within the preceding ten trials, the teacher might change criterion to two consecutive correct trials of each label within a block. Following this, the teacher can then work on one correct trial for each label and then move into random rotation from there. Mastery criterion for changing the block from two correct consecutive correct responses to one correct response is that the child performs two consecutive trials correct after making only one to two errors within the preceding ten trials. Mastery criterion for this step and for moving to the next stage, random rotation, is a correct response with each of the two objects after making only one to two errors within the preceding five trials. It is important to remember that the positioning of the stimuli on the table is randomized.

Random rotation The goal of random rotation is to randomize the order in which the teacher requests the objects, while the position of the two objects on the table is randomized. When the child is able to correctly identify the objects requested in a random order by the teacher and when the position on the table is random for 90 % of trials, then the two stimuli are considered mastered and the child has learned to discriminate the two labels. If progress at this stage is slow, the teacher might consider using a different and more systematic approach (see Other Strategies to Facilitate Discrimination Learning, below).

Increasing the field of stimuli Following completion of random rotation for the first two stimuli, the teacher starts working on the third object. This involves repeating the above stages, and the above stages can be repeated for all stimuli to be taught. The new stimulus to be taught is worked on in mass trials. Neutral distracters can then be added, before moving into block rotation, first with the first learned stimulus (in our example, car), and then with the next stimulus (dinosaur). The three stimuli can then be moved into random rotation so that the child has a field of three stimuli on the table. When the three stimuli can be placed on the table in random positions and one of the three stimuli can be asked for at random and the child is correct for 90 % of trials then the third stimulus is considered mastered.

Subsequent objects can be taught in the same way, but the field of stimuli on the table is usually kept to three. Therefore, when working on the fourth object, only two of the three previously mastered objects are used as distracters on the table at the same time. However, for the fourth object to be mastered, it has to be mixed with all of the three previously mastered objects.

Other Strategies to Facilitate Discrimination Learning

For some children, the procedures described above may not be successful. For these children, an even more systematic and incremental procedure might be required, and recent applied research has designed and validated alternative methods of teaching discrimination when traditional approaches have not been successful. Below is a description of some of those procedures.

Revised blocked-trial procedure Smeets and Striefel (1994) built on research by Saunders and Spradlin (1989, 1990, 1993), and designed a revised blocked-trial procedure. The difference between block rotation in the discrimination training procedure described above and the revised blocked-trial procedure is that the latter involves keeping the position of the items on the table in constant position while the teacher requests the items in a random order. After mastery of this step, the position of the objects on the table is gradually and systematically varied.

More specifically, in Step 1 of the revised blocked-trial procedure, the two stimuli on the table (e.g., car and dinosaur) are kept in the same positions across trials, while the objects the teacher requests ("Car" or "Dinosaur") are presented in a random order. Following 90 % or better mastery of Step 1, Step 2 involves reversing the position of the two objects on the table and maintaining those positions while the objects are once again requested randomly. Following 90 % or better mastery of Step 2, Step 3 involves changing the position of the objects on the table after blocks of four consecutive correct trials, while continuing to request the objects randomly. Finally, Step 4 involves both random location of the objects on the table and the random requesting of the objects.

Combined blocking procedure A further development of the revised blocked-trial procedure was provided by Perez-Gonzalez and Williams (2002) and by Williams et al. (2005), and has been called the combined blocking procedure. Similar to the revised blocked-trial procedure, this procedure involves keeping the position of the items on the table in constant position, but in contrast to the revised blocked-trial procedure, the order of the requests are initially *not* presented in a random order.

More specifically, in Step 1 of the combined blocking procedure, the same object (Stimulus 1) is requested in blocks of ten trials, with the objects on the table in the same location each time. After 90 % or better correct responding in a block of ten consecutive trials requesting Stimulus 1, the teacher begins requesting Stimulus 2 in blocks of ten trials (with the objects on the table in the same location each time) until 90 % or better responding is achieved. Step 2 involves reducing the blocks of trials so that the same object is requested in blocks of five trials, and with the objects on the table in the same location each time. Mastery criterion is four out of five or five out of five consecutive correct responses. Step 3 involves reducing the blocks of trials once more, this time requesting the same object in blocks of two or three trials, again with the objects on the table in the same location each time. Mastery criterion is two out of three or three out of three consecutive correct responses. In Step 4, the objects are requested at random, with the objects on the table in fixed position. Step 5 involves the same random request of the objects, but this time the position of the objects on the table is reversed and kept in the reversed location each time. Finally, in Step 6, the objects are requested at random, with the objects on the table in random position.

Random Rotation-only Procedures Recent research has examined the effectiveness of discrimination training without the initial phase of mass trialing. For some children, there may be a concern that the initial mass trialing may actually make acquisition during random rotation more difficult (Green 2001), and this was evaluated in a recent study by Grow et al. (2011). They found that starting teaching with random rotation was effective in teaching receptive labeling to three children with autism. Another recent study revealed mixed results and a 1-month follow up revealed no differences between the two discrimination teaching procedures (Gutierrez et al. 2009). In clinical practice, it is common to use the more involved discrimination training procedures early in treatment and then new programs can often be introduced with random rotation after students have acquired more highly developed discrimination repertoires. In other words, it appears that repeated discrimination training seems to establish a more generalized "ability to learn through discrimination training," often over the course of 2 or more years.

Sound Discrimination Prior research has shown that children who show deficits in the discrimination of *language* may learn to discriminate *nonverbal sounds*. For example, a child with autism may learn to point to a telephone after hearing its ring but not after hearing the word "Telephone." In a recent study, Eikeseth and Hayward (2009) assessed whether it is possible to use the sound of an object as a prompt (e.g., pointing to a telephone after hearing its ring) to teach receptive labels (e.g., pointing to a telephone after hearing the word "Telephone").

First, children who initially failed to learn receptive labels using the traditional discrimination procedure outlined above were taught to identify objects based on their sounds. Interestingly, the participants learned this discrimination quickly. Next, a fading procedure to transfer stimulus control from the sounds to the names of the objects was used. First, the teacher would state the name of one target object (e.g., "Telephone") immediately before sounding the object. Across successive trials, the teacher then faded out the sound prompt by decreasing the intensity and duration of the sound. The sound for the second object (e.g., drum) was then faded using the same procedure. Finally, the teacher presented the name of both objects in a random order (using the sound prompts when necessary) until mastery.

Discrimination Learning: Teaching Expressive Language

The procedure for discrimination training with expressive language is slightly different from that used to teach receptive language and matching. In this section, we will outline how to use discrimination training when teaching expressive language.

As an example of how we might use discrimination training to teach expressive language skills, we can consider how we might teach a social questions program. In this program, we are aiming to teach the child intraverbal skills, by asking the child a series of questions (e.g., "What is your name?", "How old are you?", and "Where do you live?"), and teaching them to provide the correct information as their response. We can begin this process in the same way that we do for receptive language programs, by first working on mass trials.

Mass trials The first question is taught in mass trials. For example, the teacher will work on repeated trials where the child is asked the question (e.g., "What is your name?") and is then prompted to give the correct response (e.g., "Tommy"). The teacher provides the child with a prompt in each trial to ensure that the child is successful and provides reinforcement for the correct response each time. As with receptive language programs, the teacher may need to start with a full prompt but in expressive language programs this may take the form of using vocal imitation so that the child repeats what the teacher tells him to say (echoic):

Teacher: “What’s your name? Say Tommy”
Child: “Tommy”

As with the receptive language program, the teacher can use a prompt hierarchy (i.e., beginning with the most intrusive prompt and ending with the least intrusive prompt) to fade the prompts, so that eventually the child can produce the correct response without prompts. This may be done, in our example, by reducing the echoic prompt and by reducing the amount of the response that the teacher says when prompting. Over time, you might see the following prompt and prompt fading:

Teacher: “What is your name? Say Tommy”
Child: “Tommy”
↓
Teacher: “What is your name? Say Tom…”
Child: “Tommy”
↓
Teacher: “What is your name? Say To…”
Child: “Tommy”
↓
Teacher: “What is your name? Say T…”
Child: “Tommy”
↓
Teacher: “What is your name?”
Child: “Tommy”

When the child has mastered giving the correct response without prompts the teacher maintains the first mastered intraverbal (“What is your name?”) and works on the second question (e.g., “How old are you?”) in separate trials in a manner identical to the first one.

Switching and random rotation When the second intraverbal is mastered and is successfully being maintained then the goal is to be able to present both the first question (“What is your name?”) and the second question (“How old are you?”) to the child in a random order, and any number of times in a row, and for the child to be able to give the correct response each time. This is random rotation and therefore, as with the receptive language program, random rotation remains the goal of discrimination training.

As described above, with receptive language programs we can use block rotation to ensure that the child continues to give the correct response (Fig. 12.1). With expressive language programs, we can again use a system of prompting, but this time using the echoic prompt each time we switch from one question to the other (if required). Because the teacher last worked on the question: “How old are you?” this question can be asked first, more than once if required, and the correct response is reinforced. Following these trials, the teacher then immediately switches to the first question (“What is your name?”) and prompts the response so that the child is correct when the question is switched:

Teacher: “How old are you?”
Child: “Four”
Teacher: “Yes, that’s good! How old are you?”
Child: “Four”
Teacher: “Right! What is your name? Say Tommy”
Child: “Tommy”
Teacher: “Good! What is your name?”
Child: “Tommy”

The teacher can repeat this process for several trials in a row and over a series of trials or sessions the teacher can fade off the prompt that is required for the switch from one intraverbal to another:

Teacher: “How old are you?”
Child: “Four”
Teacher: “Right! What’s your name? Say Tom…”
Child: “Tommy”
↓
Teacher: “How old are you?”
Child: “Four”
Teacher: “Great! What’s your name? Say To…”
Child: “Tommy”
↓
Teacher: “How old are you?”
Child: “Four”
Teacher: “Good! What’s your name? Say T…”
Child: “Tommy”
↓
Teacher: “How old are you?”
Child: “Four”
Teacher: “Fantastic! What’s your name?”
Child: “Tommy”

When the child has consistently mastered switching from one response (for question two) to a different response (for question one) then the same process can be used in reverse. The teacher asks the child for question one, reinforces the response, and then switches to question two, prompting the response with a full prompt (e.g., echoic) at first, and then fading the prompt over subsequent switches. The aim is for the child to be asked either question one or question two in any order over subsequent trials and to give the correct response each time, irrespective of which question is asked and in what order.

Individualizing and Optimizing DTT and Discrimination Training

It is crucial that each child's program is individualized to provide an optimal learning environment. For example, if procedures such as mass trials, block rotation, and random rotation are not required during DTT, then they should be left out so that the program moves forward quickly and the child does not spend time working repeatedly on responses that are already mastered simply because the child has not completed all steps in the discrimination training procedure.

In this last section of this chapter, we will discuss different strategies that can be used to optimize and individualize DTT and discrimination learning. We will begin by describing a procedure called probing, which is used to systematically assess the extent to which a child masters specific skills or items.

Probing

Probing can be used to assess whether the child has already mastered an untaught item within a program. For example, does the child know a particular untaught receptive label so that this label can be added to the list of mastered items, and so that the program can move on to teaching other object labels? Another purpose of probing is for curriculum assessment. Curriculum assessment is used to examine which part of the child's curriculum has been mastered and which parts have not. For example, probing can be used to assess whether the child can recognize body parts, which is part of the curriculum that teaches the child to respond to simple instructions. If so, body parts can be omitted and the curriculum can be moved on to target other more advanced skills.

Instead of slowly introducing each new target stimulus in a careful and systematic manner, using step-by-step procedures such as mass trials, block rotation, and then random rotation, the level of mastery of new stimuli can be assessed first by running probe trials. To do so, the new stimulus is tested in *random rotation* with two previously mastered stimuli. For example, two mastered items are placed on the table in the presence of a third novel stimulus, and the teacher asks the child for all three stimuli in random order on consecutive trials and while changing the position of the stimuli on the table. If the child can perform the correct response for the new stimulus on these probe trials, then the stimulus can be considered mastered. There is no need to spend time using discrimination training procedures and the child's program can move forward to the next stimulus to be learned.

Exclusion

Exclusion is a procedure that can be used to teach new items by allowing the child to use a "process of elimination" to work out the correct response. It is very similar to probing in that new stimuli are taught in the presence of previously learned stimuli without first using mass trials and block rotation. Exclusion is typically used within a program where the child has already learned a number of items. For example, if the child has learned a number of receptive labels, the child might be ready to learn additional labels by exclusion. The teacher places two mastered items and the new item on the table in front of the child. First, the teacher requests one of the mastered items. Next, and without changing the position of the items on the table, the teacher requests the second mastered item. Given correct responses on these two mastered items, the teacher immediately requests the unknown item, still with the position of the items on the table unchanged. Given two to three consecutive correct responses to the new item (still in the same position), the position of the items on the table is changed, and given three to five consecutive correct responses to the new item when presented on the table in random position, the teacher starts to request all three objects in a random order. Whenever mastered in random rotation, the new item is mixed with all (or most) of the previously mastered items. This is usually done by replacing one of the mastered items with another previously mastered item every time the child responds to it correctly.

Types of Antecedent Stimulus Control

During our discussion of DTT above, we have called the instructions and the task presented by the teacher an antecedent stimulus. Technically, antecedent stimuli include simple discriminations, conditional discriminations, simultaneous discriminations, and successive discriminations. Below, we will explain each type. A better understanding of stimulus control will enable the teacher to individualize the child's program even further, and will also give the teacher additional tools for designing effective discrimination training procedures when the child's learning is not progressing optimally.

Simple Discriminations (S^D) Simple discriminations occur when there is a three-term stimulus-response-consequence contingency (i.e., S^D-R-S^R contingency). For example, if a child emits the verbal response "Book" in the presence of the object book, the object book is the S^D and saying "Book" is the response. Other examples of S^D-R-S^R relations are simple intraverbals, such as fill-in-the-blank phrases like "Ready, set…" and "Peek-a-…" In this case, "Ready, set" (and "Peek-a") constitutes the S^D and the verbal response "Go" (and "Boo") constitutes the response. Also, instruction following such as waving in the response to the S^D "Wave bye-bye" is an example of a simple discrimination.

Conditional Discriminations In conditional discriminations, the three-term contingency (i.e., the stimulus-response-consequence contingency (S^D-R-S^R)) comes under the control of another antecedent stimulus, the conditional stimulus, and hence becomes a four-term contingency. The receptive labeling program outlined above is an example of a program which involves conditional discriminations. In this program, whether the correct response is to identify the car or identify the dinosaur depends on the teacher's instruction ("Car" or "Dinosaur"). Whenever the teacher says, "Car" touching the car is the correct response and touching the dinosaur is incorrect, and whenever the teacher says "Dinosaur" touching the dinosaur is correct and touching the car is not. Hence, what constitutes the correct response is conditional on another stimulus: the instruction given by the teacher. The teacher's instruction is known as the *sample* stimulus or the *conditional* stimulus and the "correct" stimulus on the table is called the S^D, and the "incorrect" stimulus (or stimuli) is called S delta (S^Δ) or S minus (S−). Thus, conditional discrimination involves the presence of a stimulus that alters the function of other stimuli.

Matching is another type of program involving conditional discriminations. In identity matching of colors, for example, the child is given a blue card to match to either a blue card or, say, a green card. The blue card that is given to the child is the conditional stimulus (or the sample stimulus), while the cards presented on the table (blue and green) are the S^D and the S^Δ. When the child is given the blue card, only the identical blue card is the correct match, and therefore that stimulus is a discriminative stimulus (S^D or S+). The other cards with other colors are not associated with reinforcement when given a blue card to match with the blue card and are therefore an S^Δ or S−. Hence, which of the stimuli on the table is a discriminative stimulus is conditional upon which sample stimulus is given to the child, and therefore this is a conditional discrimination.

Simultaneous Discriminations and Successive Discriminations Another factor that is relevant when teaching is whether the stimuli involved are present simultaneously in time, or if they occur one after the other. This is called simultaneous and successive discriminations, respectively.

The receptive labeling program involves a simultaneous discrimination of the S^D and the

S^{Δ} because the child selects one of several items presented on the table simultaneously in time. For example when hearing "Touch cup," the child selects the object cup amongst other items that are present simultaneously on the table, and choosing between the available items involves a simultaneous discrimination. However, receptive labeling also involves a successive discrimination. This is because the stimulus spoken by the teacher (e.g., "Touch cup" and "Touch ball") occurs across trails. Hence, responding to the conditional stimulus (sample stimulus) involves a successive discrimination and responding to the S^{D} and the S^{Δ} involves a simultaneous discrimination.

Curriculum and Types of Stimulus Control

As evident from the above, even relatively simple skills might involve complex stimulus control issues. To further illustrate this, we have examined a typical beginning language curriculum and described what types of stimulus control are involved in each of the programs. This is illustrated in Table 12.2. The curriculum skills listed in the left hand column are:

- Identity matching: Placing identical stimuli together in a match-to-sample procedure.
- Nonvocal imitation: The child watches and copies a range of actions performed by the teacher, including actions with objects, and gross, fine, and oral motor movements.
- Receptive instructions: The teacher gives instructions for the child to follow (e.g., "Wave" or "Clap hands")
- Receptive labels: The teacher gives the child an instruction to select a stimulus (e.g., "Give me car" or "Give me hat").
- Vocal imitation: The child listens to a vocal stimulus presented by the teacher (e.g., a sound, word, or sentence) and speaks it back to the teacher.
- Expressive labels: The child is shown an object and the child names it correctly.
- Simple intraverbals: Fill-in-the-blank phrases, such as "Ready, set…," "Peek-a-…," "A, B…," "1, 2…," "big…"

The remaining columns show the type of stimulus control involved in each program (simple, conditional, simultaneous, and successive), the type of stimuli involved, and the relation between stimuli and responses.

A *cross-modal relation* exists, for example, when a child sees something that he/she desires (e.g., an apple) and requests it (i.e., says "Apple"). In this case, the stimulus (apple) is visual, and the response (i.e., requesting the apple) is a verbal response that also is auditory because the child can hear him/herself speaking. In addition, saying "Apple" is a motor response because each word has a distinct oral motor topography. Hence, saying "Apple" when you see an apple is a cross-modal relation consisting of a visual stimulus and a verbal-auditory motor response.

Receptive instructions, where the teacher gives instructions for the child to follow (e.g., "Wave" or "Clap your hands"), also involves a cross-modal relation, where the S^{D} "Wave" is a verbal auditory stimulus and the response involves a gross motor action that is distinct for that particular S^{D}. Clapping, in contrast, involves a gross motor topography that is different from waving. In addition, clapping is visually distinct from waving.

Nonvocal imitation involves cross-modal relations where the stimulus is visual (e.g., the teacher demonstrates clapping) and the response involves a gross motor action that is distinct for that particular S^{D} (e.g., the child claps).

An arbitrary related stimulus is a stimulus that bears no relation to the form of other stimuli present, such as all verbal stimuli, written or spoken. The written word CAR bears no resemblance to the object car. Similarly, the spoken word "Car" bears no resemblance to the object car or the sounds it makes. Hence, they are arbitrarily related stimuli. As described above, research has shown that children with autism may readily learn object discriminations based on the objects' sound, but show difficulties establishing object discriminations when required to respond to the names of the objects (Eikeseth and Hayward 2009). The object name is an arbitrary related verbal auditory stimulus, whereas the object sound is a nonarbitrary and nonverbal auditory stimulus.

Table 12.2 For the skills that are typically taught to children with autism at the beginning of their programs (left hand column) the ticks indicate those types of discrimination that may be involved in learning the skill, together with other types of stimuli that may be present during acquisition of the skill

Skill	Antecedent stimuli and responses						
	Simple discrimination	Conditional discrimination	Simultaneous discrimination	Successive discrimination	Stimulus and response relation	Arbitrarily related	Vocal stimulus
Identity matching	No	Visual CS and visual $S^D$and the S^Δ	$S^D$and the S^Δ	CS	CS: Visual S^D: Visual R: Motor *without* a unique response topography	No	No
Nonvocal imitation	Yes	No	No	S^D	S^D: Visual R: Motor *with* a unique response topography	No	No
Receptive instructions	Yes	No	No	S^D	S^D: Verbal (auditory) R: Motor *with* a unique response topography	Yes	Yes
Receptive labels	No	Verbal CS and visual S^D and the S^Δ	S^D and the S^Δ	CS	CS: Verbal (auditory) S^D: Visual R: Motor *without* a unique response topography	Yes	Yes
Vocal imitation	Yes	No	No	S^D	S^D: Verbal (auditory) R: Verbal *with* a unique response topography	No	Yes
Expressive labels	Yes	No	No	S^D	S^D: Visual R: Verbal *with* a unique response topography	Yes	No
Simple intraverbals	Yes	No	No	S^D	S^D: Verbal (auditory) R: Verbal *with* a unique response topography	Yes	Yes

As can be seen in Table 12.2, if the child learns *identity matching*—which is one of the most basic programs of the beginning curriculum—the child is able to perform conditional discriminations.

Nonvocal imitation of gross motor actions—also a beginning curriculum program—involves successive discriminations. If the teacher continues to demonstrate the action until the child responds, it is a simultaneous discrimination. If, on the other hand, the teacher shows the action only briefly to the child and stops demonstrating it before the child responds, it is a delayed discrimination. Presenting the S^D so it occurs while the child emits the response may help the child acquire this skill.

Nonvocal imitation also involves cross-modal relations because the action is demonstrated visually to the child and the child's response is a motor response.

Receptive instructions are simple discriminations, and involve successive discriminations. Also, since the S^D "Clap" is not present while the child performs the response, it is also a delayed discrimination. It is also a cross-modal relation, where the instruction given by the teacher is verbal auditory and the child's response is motor.

Receptive labeling is often a more difficult skill to learn when compared to receptive instructions. This might be surprising since they both involve responding to verbal stimuli. However, the two programs differ in at least two important ways. Firstly, receptive labeling involves conditional discriminations whereas receptive instructions involve simple discriminations. Secondly, they differ in their response dimension in that receptive labels involve a selection response, while receptive instructions involve a motor response where the repose topography is unique to the S^D. Receptive labels involve selecting the target item placed in any position, and this selection is based merely on the form of the item. Receptive instructions, in contrast, involve distinct response topographies for each individual instruction given. The response topography for the instruction "Touch head" is touching the head, and the response topography for the instruction "Clap" is clapping, and clapping and touching the head are two different responses. Research suggests that discriminations involving visual-motor responses are easier to learn as compared to discriminations involving visual responses (Potter and Brown 1997). This knowledge can be used to design effective programing changes that may help a particular child acquire receptive labels, by altering the response topographies to become topography based. This can be done by requiring distinct response topographies for each object taught. For example, the child might be required to identify the car by driving it, to identify the cup by pretending to drink from it, and to identify the book by opening it.

In addition (or alternatively), using the sound discrimination procedure outlined above (teaching the child first to respond to an auditory nonverbal stimulus (object sounds) and subsequently fading in the object's name and fading out the object's sound) might facilitate learning of receptive labels.

Expressive labeling involves simple discriminations and successive discriminations. Expressive labels involve the presence of a visual stimulus and a vocal verbal response from the child. It is a cross-modal relation because the S^D is visual and the response is verbal.

Simple intraverbal behaviors involve simple discriminations and successive discrimination (e.g., answering "Go" in response to the S^D: "Ready, set…"). It is also a cross-modal relation where the S^D is auditory verbal and the response is a verbal vocal motor response.

As evident from the above, even the beginning curriculum involves complex discriminations and complex stimulus control issues. By using this knowledge, together with knowledge about which curriculum skills the child is acquiring and what part of the curriculum the child has difficulties with, the teacher may be equipped to problem solve and individually tailor teaching programs for each particular child. This in turn might help the child overcome these learning difficulties. Hence, the stimulus control technology available from behavior analysis is a helpful tool for facilitating learning in children with developmental delays of different degrees and for different reasons. By analyzing the type of stimulus control involved in each type of curriculum skill, and by examining which skills the child is learning and which type of skills the child has difficulties learning, the teacher may be able to perform a type of *functional analysis of stimulus control,* which in turn can be used to individualize the child's program to maximum effect. Such an approach would constitute a careful analysis of each student's learning in terms of the behavioral processes at work, rather than a merely application of procedures and technology.

Summary and Future Research

DTT is an instructional procedure designed to improve the developmental and educational outcomes of children with autism and other developmental delays and is an important component of contemporary EIBI programs. DTT is a highly validated procedure and has been used to help children with autism acquire a wide range of skills including language, imitation, play skills, and social and emotional skills. In addition, DTT has been used to reduce aberrant behavior. DTT differs from other teaching methods in its focus on errorless learning, the large number and speed of repetition, the high degree of structure, and the arbitrary connection between task and reinforcement. This enables DTT to teach children who have not learned spontaneously in normal settings to acquire basic behaviors and discriminations necessary for continued development in normal settings.

Discrimination training is an important element of DTT. Discrimination training deals with the way in which training stimuli and prompts are presented and how prompts are subsequently removed, and a number of different discrimination training strategies exist to promote learning. It is clear from previous research, from an examination of the types of discrimination involved, and from an examination of the stimuli present in the relatively simple programs outlined in Table 12.2, that there are many elements that are present in all programs and that exert an effect on the ability of a child to master the skill being taught. Future research should be conducted to examine the role that different types of discriminations play in the learning of new skills by children with autism. Research could examine the effectiveness of working on skills using simultaneous discrimination procedures rather than successive discrimination procedures. Further, the type of stimulus that is present can be evaluated by examining the effects of changing arbitrary vocal stimuli into nonarbitrary auditory stimuli to teach children to discriminate different sounds as a prerequisite to discriminating vocal stimuli. The implications that this research has for treatment and teaching programs for individuals with different types of learning difficulties is potentially wide-ranging.

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Natural Environment Training

13

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Naturalistic instruction · Pivotal response training · Incidental teaching

Traditional structured teaching paradigms that utilize the principles of applied behavior analysis (ABA), such as discrete trial training (DTT), have proven to be very successful in addressing the behavioral deficits and excesses of children with autism spectrum disorder (ASD; National Research Council 2001). However, such interventions often have been plagued with prompt dependence, reduced child motivation, and a lack of child generalization and maintenance of acquired skills (Brunner and Seung 2009; Matson et al. 1996; Smith 2001). Subsequently, naturalistic behavioral approaches were developed to address these limitations while simultaneously preserving the use of the principles of ABA and adhering to the following rules of intervention implementation (Matson et al. 1996; Mirenda and Iacono 1988; Mundy and Crowson 1997). Naturalistic behavioral approaches typically require that the intervention be applied in the child's natural environment, is child initiated, involves materials and activities that are child selected, targets general (as opposed to specific) behaviors, utilizes loosely applied prompt strategies and reinforcement contingencies, and applies natural reinforcement (Cowan and Allen 2007; Ingersoll 2010b).

Naturalistic behavioral approaches to intervention are designed for children with ASD and have a solid evidence base in the literature, earning an "established" evidence level from the National Research Council (2001), the National Autism Center (2009), and the National Professional Development Center on Autism Spectrum Disorders (2011). These treatments are effective for teaching language, play, and social skills in children, adolescents, and even adults with ASD (Goldstein 2002; Matson et al. 1996; Schreibman and Anderson 2001). This chapter will provide an overview of the naturalistic behavioral approaches available for the treatment of children with ASD and will identify current and future directions in behavioral intervention research.

Naturalistic Behavioral Approaches

Incidental Teaching

Perhaps the "original" form of naturalistic behavioral intervention is incidental teaching (IT),

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which was developed in the 1960s to increase the language skills of underprivileged children in preschool settings (Hart and Risley 1968). According to Hart and Risley (1982), IT includes first arranging the child's natural environment to include toys and activities of interest that are visible to the child but not accessible without assistance or support. The teacher's behavior in IT follows the following steps: (1) wait for the child to initiate (likely to obtain help, permission, attention, and/or approval), (2) respond to the child's initiation immediately, (3) verify if unsure of what the child wants after initiation, (4) request the child to elaborate the initiation, (5) prompt and (if necessary) model the elaborated response if the child does not comply, and (6) verbally confirm the child's request while providing access to the preferred toy or activity contingent on the child's elaborated response. Hart and Risley reported impressive improvement in many aspects of the speech of the preschool children in their studies (Hart and Risley 1968, 1974; Risley and Hart 1968). Further, they found the children showed generalization of these language improvements that was superior to the generalization of language skills taught during highly structured training sessions (Hart and Risley 1980).

In the 1980s, researchers began in earnest to investigate the utility of IT for the treatment of communication deficits in children with ASD (Green 2001). Early research documented the successful use of IT to teach acquisition and generalization of receptive object labels (McGee et al. 1983), reading (McGee et al. 1986), and sign language (Schepis et al. 1982). In addition, comparison studies examining the difference between teaching expressive use of prepositions and labels to children with ASD using IT procedures versus using traditional structured teaching procedures revealed greater generalization and more spontaneous use of the prepositions and labels taught with IT procedures (McGee et al. 1985; Miranda-Linne and Melin 1992). Despite these promising findings, many children with ASD have difficulty spontaneously initiating interactions with others, even to request preferred items (Mirenda and Iacono 1988). IT learning rates may be slower for these children because there may be limited opportunities for learning if the teacher is required to wait for the child's initiation. (Rogers-Warren and Warren 1980).

In order to address this limitation, researchers have begun to adapt the original IT paradigm to better address the specific needs of children with ASD (Haring et al. 1987; Mirenda and Iacono 1988). For example, the modified incidental teaching sessions (MITS) procedure, developed by Charlop-Christy and Carpenter (2000), addresses decelerated child learning as a result of a lack of spontaneous child initiations by allowing mand-model adult initiations (e.g., adult encourages the child to request a preferred object by asking "What do you want?" and then models the appropriate complex response if needed). Charlop-Christy and Carpenter (2000) also modified traditional IT by utilizing parents as implementers of the MITS in the home environment in order to further facilitate generalization. In a comparison study of traditional IT, MITS, and DTT, these authors used a multiple baseline design across subjects in combination with an alternating treatment design to determine the effect of MITS training on three children with ASD. They found that all children showed better acquisition and generalization of the target behaviors learned in the MITS condition as compared to the traditional IT and DTT conditions (Charlop-Christy and Carpenter 2000).

Milieu Teaching

Originally developed as a specified combination of research-supported interventions to teach language to children with language delay, milieu teaching (MT) was quickly accessed as an intervention option to address communication deficits in children with ASD (Mancil 2009). MT comprises four well-established teaching techniques: (1) modeling and then correcting the child's behavior if necessary, (2) the mand-model technique described previously, (3) time delay, as the adult will wait for a predetermined amount of time after presenting the stimulus for the child to respond, and (4) all components of IT

(Kaiser et al. 1991; Mancil 2009). Kaiser et al. (1992) reported MT to be effective for teaching language skills ranging from single words to complex phrases to children and adolescents with language delay, intellectual disability, or ASD. In addition, the acquired language skills generalized across various settings and trainers in several of the studies (Kaiser et al. 1992).

However, as with other naturalistic behavioral approaches, traditional MT has been modified over time to better accommodate the specific needs of children with ASD. Enhanced milieu teaching (EMT) consists of all of the components of traditional MT with the addition of increased language expansions, turn taking, and following the child's lead. Hancock and Kaiser (2002) implemented a multiple baseline across subjects design to examine the effects of EMT on four children with ASD. All the children showed increases in their language targets that were maintained at a 6-month follow-up. The children also increased the complexity and diversity of their language. In addition, three out of four of the children generalized their acquired language skills to their home environment. In order to address the needs of children with ASD who have not developed vocal language, prelinguistic milieu teaching (PMT) utilizes the techniques of MT to specifically teach valuable preverbal communication skills such as gestures, vocalizations, and coordinated eye gaze (Fey et al. 2006; Yoder and Stone 2006). In addition, Franco (2008) used PMT to successfully teach school-age children with ASD to increase the frequency and clarity of their communication skills in a home setting.

Pivotal Response Training

Pivotal response training (PRT), sometimes referred to in the literature as pivotal response treatment, is a child-directed therapy well supported as an established evidence-based practice intervention for children with ASD (e.g., Humphries 2003; National Autism Center 2009; National Research Council 2001; National Professional Development Center on Autism Spectrum Disorders 2011). PRT is an expansion of the natural language paradigm (NLP; Gillett and LeBlanc 2007; Laski et al. 1988), a language intervention originally developed as a combination of traditional operant and naturalistic procedures for children with ASD. NLP is presented in a naturalistic teaching paradigm where child choice, task variation, flexible prompting, and reinforcement of child attempts are valued. Comparisons of the NLP and more traditional structured teaching revealed the NLP to provide improved generalization and spontaneity of child language gains (Koegel et al. 1987).

PRT targets the "pivotal" behaviors of motivation and responsivity to multiple environmental cues (Koegel et al. 1989). Pivotal behaviors are so-named because improvements in these behaviors are likely to affect change in collateral behaviors, which may improve overall child response to treatment and minimize the treatment time required to learn new skills. Motivation is a pivotal behavior for children with ASD because increasing child motivation during intervention will likely lead to increased language, play, and social gains (e.g., increasing a child's motivation to respond to social approaches can reduce avoidance of social learning opportunities). It is often challenging to access high levels of child motivation during treatment. PRT seeks to address limited child motivation levels directly (Koegel et al. 1999; Schreibman 1988). For example, PRT targets child motivation by consistently following the child's lead including when to play, what to play, and how to play. All intervention is provided in the context of a child's individual interests and preferences. In addition, difficult tasks are interspersed with easier tasks and children are reinforced for good attempts at the target behavior to help create behavioral momentum.

Children with ASD also exhibit difficulties with "stimulus overselectivity" (Lovaas et al. 1979, 1971; Schreibman 1988), an attentional deficit wherein the child does not respond to simultaneous stimulus input. Stimulus overselectivity may limit a child's ability to generalize previously learned behavior out of the intervention context (Schreibman 1997). Fortunately, research supports that many children with ASD who display overselectivity can in fact learn to respond to compound stimuli if taught a series of conditional discriminations (i.e., discrimination tasks requiring response to simultaneous multiple cues; Koegel and Schreibman 1977; Schreibman et al. 1982, 1977). PRT addresses stimulus overselectivity directly as another pivotal behavior by teaching children to respond to multiple cues simultaneously, thus removing a barrier to generalization.

Subsequent research has identified self-initiation and self-management as pivotal behaviors in addition to motivation and responsivity to multiple cues. Self-initiation is considered a pivotal behavior as it allows a child with ASD to spontaneously approach others to manipulate her environment for a variety of reasons (e.g., to obtain items or engage in social interaction), providing the child with a wealth of learning opportunities. Education in self-management allows an individual with ASD to monitor her own behavior and provide appropriate consequences in order to manage her own behaviors. Individuals with ASD have effectively utilized self-management to increase desirable target behaviors (e.g., language, play, and social skills) and decrease undesirable target behaviors (e.g., stereotypic behavior; Cowan and Allen 2007; Matson et al. 1996).

PRT is typically implemented during play but is a highly flexible intervention that can be used throughout the child's day wherever there is a learning opportunity. As noted, the key components of PRT focus on increasing the pivotal behaviors of motivation and responsivity to multiple cues. These components include how to deliver the opportunity for a target behavior by: (1) providing the child clear instructions or questions that are relevant to the current task or activity, (2) interspersing easy tasks with difficult tasks, (3) allowing child choice of activity or objects used during sessions, (4) taking turns with the child, and (5) presenting learning opportunities that require the child to respond to simultaneous multiple stimuli (i.e., conditional discriminations). PRT also addresses how to respond to the target behavior once it occurs by: (6) utilizing direct or natural reinforcement, (7) ensuring reinforcement is contingent, and (8) reinforcing appropriate attempts to respond (Koegel et al. 1989). Multiple single-subject and long-term outcome studies have confirmed that PRT facilitates the functional use of language for many children with ASD, including those with little to no functional speech (Humphries 2003; Koegel et al. 1987, 1999a, b; Laski et al. 1988). Moreover, when compared with more structured behavioral techniques, the specific components of PRT facilitate relatively greater increases in verbalizations and spontaneous language use (Delprato 2001; Koegel et al. 1988; Koegel and Williams 1980; Williams et al. 1981).

In addition to language acquisition, PRT has been shown to be effective for targeting play and social skills in children with ASD (Pierce and Schreibman 1997a, b; Stahmer 1999). Stahmer (1995) taught seven children with ASD to engage in symbolic play behaviors using PRT. She found that after receiving PRT targeting symbolic play, children with ASD engaged in symbolic play at levels comparable to typically developing children of the same language ability. In addition, the children increased their interactions with adults during play. The children also generalized these skills to new toys, adults, and settings and maintained skills over time. Thorp et al. (1995) targeted sociodramatic play using PRT with three children with ASD. Sociodramatic play consists of the interaction of a group of children cooperating to elaborate together around a central theme, and the study found that PRT was effective in increasing this form of play. Importantly, in addition to their improved play skills, the children showed collateral improvements in language and social skills.

Reciprocal Imitation Training (RIT)

Reciprocal imitation training (RIT; Ingersoll and Gergans 2007) draws from naturalistic behavioral approaches such as IT, MT, and PRT to specifically teach imitation skills to children with ASD using contingent imitation (imitation of the child's movements and vocalizations), linguistic mapping (narrating the child's play), and imitation training (modeling actions, prompting, and reinforcement). Targeting imitation skills during an early intervention program may help children with ASD learn a wide range of other functional behaviors (Ingersoll 2010b; Schreibman 2005). RIT has been used to successfully teach joint attention (Meindl and Cannella-Malone 2011), play (Stahmer et al. 2003), object imitation (Ingersoll and Schreibman 2006), and descriptive gestures to children with ASD (Ingersoll et al. 2007). In fact, in the RIT studies where the authors targeted object imitation and descriptive gestures, the treatment gains generalized to new therapists, settings, and materials, and maintained at a 1-month follow-up. In addition, although only imitation skills were targeted, Ingersoll and Schreibman (2006) found collateral effects of RIT on language, pretend play, and joint attention skills of the five children with ASD in their study. In a randomized controlled trial, Ingersoll (2010a) found that RIT was effective at increasing object and gesture imitation skills in a group of children with ASD in comparison to a control group, replicating the previous single-subject research findings.

Implementation

Naturalistic Teaching in the Classroom

In a very promising direction of application, naturalistic behavioral approaches have been effectively utilized in classroom settings. Lerman et al. (2004) found increases in student communication behaviors after providing teachers with a week-long workshop, approximately 18 h of training, where IT was one component (teachers were also taught other behavioral techniques like preference assessment and direct teaching). Teachers were provided lectures, handouts, role-playing with feedback, and in vivo practice with feedback. All intervention skills learned generalized to other students in the classroom. There is some evidence to show teacher acquisition of IT skills can be accomplished with less training time. Haring et al. (1987) taught teachers some IT procedures with only self-instruction materials including daily preplanned activities. In their study, teacher self-monitoring was enough to increase maintenance and generalization of IT skills in the classroom. Ryan et al. (2008) found that a brief 30-min group IT training that included didactic lecture, modeling, and role-playing with feedback was similarly effective as multiple individualized training sessions for training teachers to use IT to increase student initiations in the classroom. In addition, the teachers rated IT favorably and reported it useful (Ryan et al. 2008).

IT is the primary intervention used at the Walden Early Childhood Program, an inclusion program for children with ASD (McGee et al. 1999). The Walden Early Childhood Program consists of multiple classrooms: toddler, early preschool, preschool, and pre-kindergarten serving typically developing and children with ASD up to 4 years of age. The Walden model has been replicated at multiple sites (McGee et al. 1999). Teachers in all classrooms are trained to utilize IT during all activities throughout the day and the classroom environment is conducive to implementation of IT (e.g., preferred items are observable but inaccessible to the children and gates divide areas of the classroom to facilitate child requests to move from area to area). Children with ASD who have attended the Walden Early Childhood Program have shown good language and social skill outcomes (McGee et al. 1999).

In addition to teachers, paraprofessionals (often described as classroom aides) can effectively use naturalistic behavioral approaches to improve child behaviors in the classroom. Robinson (2011) taught paraprofessionals to utilize PRT using a 45-min modeling session and subsequent video-based feedback sessions. During the video-based feedback sessions, a PRT trainer and paraprofessional watched videotapes of the paraprofessionals utilizing PRT together while the PRT trainer provided feedback. The paraprofessionals greatly improved their PRT implementation and the author also found increased social-communication behaviors of the children with ASD in the target classroom. In addition, Robinson (2011) found good maintenance and generalization of the PRT implementation skills of the paraprofessionals. When surveyed about the PRT training they received, the paraprofessionals reported that they were completely satisfied with the training protocol and felt better able to help their students with ASD after training.

Social validity (i.e., social importance and acceptability; Foster and Mash 1999) is an important consideration for interventions intended for classroom use, as social validity can greatly impact effective dissemination (Stahmer 2007). There is some evidence that naturalistic behavioral approaches such as PRT may be more difficult for teachers to implement than traditional structured teaching techniques (Zandi et al. 2011). However, Lerman et al. (2004) found that teachers in their study showed better acquisition of IT techniques than of direct teaching techniques during their teacher training sessions. Despite mixed research findings regarding the ease of teacher adoption of naturalistic behavioral approaches, successful dissemination of these approaches is essential given their potential for improved child maintenance and generalization of acquired skills. Thus, in order to ease the transition of PRT from the laboratory to the classroom, an adaption of PRT called classroom pivotal response teaching (CPRT; Stahmer et al. 2011) has been developed by intervention researchers in a collaborative relationship with classroom teachers. CPRT is currently under careful study to determine if the adjustments made will simultaneously uphold the integrity and positive student outcomes of the intervention while allowing PRT to be more easily translated into the classroom setting (Stahmer et al. 2011).

Parent-Implemented Intervention

Educating parents of children with ASD to implement naturalistic behavioral interventions can be highly beneficial, as parent-implemented naturalistic behavioral approaches may improve child outcome. There are several specific benefits of parent education. First, children spend the majority of their time with their parents, thus providing a wealth of valuable intervention opportunities. Second, training parents saves families and the service system time and costly resources because parents can provide treatment themselves instead of utilizing outside resources. Third, such training can reduce parent frustration levels by allowing parents to better manage their children's challenging behaviors. Fourth, parent training can improve child generalization and maintenance of skills learned in intervention (Kaiser 1995; Koegel et al. 1996; National Research Council 2001; Symon 2005).

There is a great deal of evidence in the literature to support the effectiveness of a parent education component for the naturalistic behavioral approaches mentioned thus far. Parents have effectively utilized MIT (Charlop-Christy and Carpenter 2000; Kaiser et al. 1995) and EMT (Kaiser et al. 2000) to increase communication by their children with ASD. Parents have also learned to implement PRT to improve communication (Coolican et al. 2010; Minjarez et al. 2011), as well as adaptive functioning (Baker-Ericzén et al. 2007), and joint attention skills (Rocha et al. 2007). Ingersoll and Gergans (2007) successfully trained three parents to use RIT to teach spontaneous object and gesture imitation to their children with ASD.

In addition to well-documented parent and child gains during treatment, most of the above parent implementation studies measured generalization and maintenance of parent and child skills after treatment concluded. Overall, the majority of the parents and children in these studies were able to generalize skills learned from the clinic to the home setting and often these skills were maintained over time for both the parents and the children. Recent research also suggests that parent education in naturalistic strategies can be conducted in less time (Coolican et al. 2010) and more easily (Minjarez et al. 2011) than originally thought. For example, parent education programs typically consist of parent education implemented over many individual sessions. Minjarez et al. (2011) successfully utilized a group training format over 10 weeks to instruct 17 parents to implement PRT to improve the communication skills of their children with ASD. The parents in their study learned to implement PRT with high levels of fidelity and their children showed associated gains in functional language.

Naturalistic behavioral approaches are particularly well suited to parent education programs as they are implemented in a variety of natural settings and circumstances and at different times of day. Thus, it is not surprising there is some evidence that parents may favor such an approach over more traditional structured teaching approaches. For example, Schreibman et al. (1991) found that parents implementing PRT exhibited more positive affect (i.e., parent enthusiasm, interest, and happiness) than parents implementing traditional DTT with their children with ASD when rated by naive observers during a parent education program. The authors propose the parent affect difference may be the result of the more “natural” interaction style of a naturalistic behavioral approach such as PRT over the more contrived style of a traditional structured approach such as DTT. They also suggest the improved parent affect may be due to increased child motivation during intervention sessions that is directly targeted with PRT (Schreibman et al. 1991).

Peer-Implemented Intervention

In addition to parents as interventionists, educating peers (peer tutors) to implement naturalistic behavioral approaches for individuals with ASD (peer learners) can be valuable for several reasons. Peers are often readily available in the individual’s natural environment and the availability of peers as interventionists provides more opportunities for learning. Educating peers to be interventionists is relatively easy and educating peers may foster better inclusion, as individuals with ASD will have more experience interacting successfully with their peers. In addition, typical peers may provide better models for age-appropriate language, play, and social skills than other interventionists, and utilizing peers themselves as interventionists may improve generalization and maintenance of language, play, and social skills to community settings such as school where peers will be present (Chan et al. 2009; Pierce and Schreibman 1997a, b).

Typically, these approaches consist of the peer trainer modeling and role-playing the intervention techniques for the peer tutor, providing feedback to the peer tutor, and providing the peer tutor with a visual checklist composed of words or pictures to ensure proper implementation. Then the trainer fades herself from the intervention sessions slowly when the peer tutor is comfortable with the intervention and is reliably implementing the intervention with acceptable fidelity levels. In addition, peer trainers may provide reinforcement (often in the form of a token system) to the peer tutors contingent on their use of the intervention with the peer learners in the natural environment. Peer tutors utilizing naturalistic behavioral approaches to intervention for peer learners with ASD are often taught to wait for the peer learner to initiate toward an item (e.g., reach, look at), ask the peer learner for a target behavior (e.g., label, point), provide the item when the peer learner exhibits the target behavior, and praise the peer learner after a successful interaction. Peer tutors are also taught to provide prompts as needed and take turns with the peer learner to increase opportunities for interaction (Chan et al. 2009).

Research has supported the effectiveness of these strategies, as peer tutors of various ages have been successfully taught to provide naturalistic behavioral interventions to peer learners with ASD. For example, typical preschool children were taught to use IT with three children with ASD during free play in their classroom, subsequently increasing the peer learners’ use of verbal labels and reciprocal interaction during play (McGee et al. 1992). After training, the peer tutors themselves also increased their approaches toward children with ASD. Generalization of these research findings were mixed in their study, but the teachers and peers involved in the study rated the intervention favorably. Farmer-Dougan (1994) reports successfully utilizing IT-trained adult peer tutors of adult peer learners with intellectual disability and ASD in a group home setting to increase appropriate requests during lunch. She found good generalization of the learned skills for the adult peer tutors and the adult peer learners from lunchtime to dinnertime.

In addition, there was a promising increase in the overall interactions between all the residents and staff.

Typically developing peer tutors also have been taught to use a modified version of PRT to increase social interactions, initiations, toy play, and language skills in peer learners with ASD. Pierce and Schreibman (1997a, b) designed a manual specifically to teach the components of PRT to school-age peer tutors, with simple pictures and words. Peer trainers also explained and modeled the PRT techniques, role-played, gave feedback to the children, and subsequently faded themselves from the classroom. In addition to language and social skill gains during treatment, fairly good generalization was observed (Pierce and Schreibman 1997a, b).

Sibling-Implemented Intervention

Perhaps the best peer tutor option for a child with ASD is his/her own sibling. Compared with siblings of children with other developmental disabilities such as Down syndrome, siblings of children with ASD report less emotional closeness and are more pessimistic about their affected siblings' future (Orsmond and Seltzer 2007). The mechanism of this disparity is not clear, but may possibly be ameliorated by educating siblings to serve as "sibling tutors" for their siblings with ASD (Henderson 2010; Schreibman et al. 1983; Smith and Elder 2010). The limited research available on sibling tutors suggests that educating siblings to act as interventionists may be beneficial for children with ASD as well as their siblings (Henderson 2010; Smith and Elder 2010).

Sibling tutors have successfully learned to implement various behavior modification techniques such as prompting, shaping, reinforcement, modeling, responding to initiations, and turn taking to improve their interactions with their siblings with ASD during play (Kim and Horn 2010; Schreibman et al. 1983). After sibling tutors began to use the behavioral techniques, their siblings with ASD showed subsequent improvements in social skills (Tsao and McCabe 2010; Tsao and Odom 2006), appropriate play skills (Celiberti and Harris 1993), and communication skills (Schreibman et al. 1983) that often maintained over time and generalized to new settings. Sibling tutor training is often implemented as other peer intervention training programs, usually consisting of 1:1 instruction, modeling, role-playing, and feedback during practice (Ferraioli and Harris 2011). In one study, parents themselves served as trainers of their own typically developing children to intervene with their siblings with ASD. Parents successfully taught the sibling tutors to gain their sibling's attention, model appropriate play, maintain the interaction, and provide praise after a successful interaction. As a result, they saw improved sibling interactions overall in the home during play (Strain and Danko 1995).

Most sibling-implemented intervention research focuses on educating siblings to utilize individual components of behavioral intervention strategies. More recent research has focused on utilizing sibling tutors to successfully implement complete naturalistic behavioral approaches such as PRT combined with components of DTT (Ferraioli et al. 2011). Ferraioli et al. (2011) stress the importance of using naturalistic behavioral approaches for sibling tutor training as educating siblings in a naturalistic setting may reduce the demands on the sibling and the child with ASD during intervention. Ferraioli and Harris (2011) taught sibling tutors to utilize a PRT and DTT combination intervention to increase joint attention skills in their siblings with ASD. They also found the joint attention skills learned by the children with ASD maintained and generalized to adults in other settings. Collateral effects of the training included increases in rates of imitation and behavioral requests during play for the children with ASD (Ferraioli and Harris 2011).

More research in this area is certainly warranted as addressing the impact of having a sibling with ASD is important for sibling tutors. Sibling tutors would be greatly impacted, as they are more likely to be readily available as interventionists than other peers. Providing siblings with the opportunity to have an active role in their siblings' intervention programs may afford siblings of children with ASD an outlet for their willingness to help and be involved in intervention

(Henderson 2010; Smith and Elder 2010). In fact, teaching siblings of children with ASD the behavior modification procedures of reinforcement, shaping, chaining, and discrete trial increased the sibling tutors' positive statements about their siblings with ASD (Schreibman et al. 1983).

Acting as a sibling tutor may make a sibling more satisfied with the sibling relationship as the sibling with ASD will be more likely to respond to a sibling's initiations after training which can increase overall engagement for both children during play. These effects may strengthen the sibling bond and provide a wealth of intervention benefits, as the sibling is prone to be an ideal behavior model and source of reinforcement for the child with ASD. Also, because the sibling tutor is likely to be present in most other environments where the child with ASD spends time, an increase in maintenance and generalization of skills learned in intervention sessions may be expected. In addition, parents of the sibling dyads may also benefit from sibling tutor training, as it may be less necessary to monitor their children's interactions (Ferraioli et al. 2011). Of course, one must also be aware of potential negative effects of this expectation of participation of siblings since the added responsibility, and possible stress, might not make it a suitable treatment approach in all cases. If no clear benefit to the sibling tutors can be identified, reinforcement strategies can also be applied to the sibling tutors to ensure a positive experience (Ferraioli et al. 2011).

Current and Future Directions for Research

Upcoming intervention research on naturalistic behavioral approaches will ideally focus on identifying methods to maximize treatment effectiveness for children with ASD. One way to improve intervention programs may be to adjust or combine effective treatments to target a child's specific needs (Schreibman and Anderson 2001). For example, EMT can be augmented for use with children who have very limited language skills. Olive et al. (2007) combined EMT with a voice output communication aid to improve communication skills in three nonverbal children with ASD within a multiple-baseline probe design. All children learned to use the voice output communication aid to request during play and one child even began to vocalize. Mancil et al. (2009) combined MT with functional communication training in order to simultaneously teach functional communication skills and reduce disruptive behavior in three children with ASD. All the children increased their communication and decreased their disruptive behavior, which maintained over a short follow-up time period and generalized from the home to the classroom.

Intervention programs can also be augmented to address specific parent variables in order to maximize child benefits from treatment. For example, Yoder and Warren (1998) determined that amount of maternal responsivity influences the child's generalization of intentional communication skills learned during PMT for children with developmental disabilities. Children whose mothers were more responsive to the intentional communication skills that the children learned during a course of PMT helped increase the children's generalization of these skills to the home. To address this finding, Yoder and Stone (2006) utilized a responsive education component in addition to PMT, which encourages parents to talk and play with their children to facilitate language learning.

Traditional structured teaching interventions may have an initial advantage over naturalistic behavioral approaches to intervention for more rapid acquisition of skills (Cowan and Allen 2007). However, the benefits of naturalistic behavioral approaches may outweigh an early acquisition advantage by providing better maintenance and generalization of skills learned over time. In a comparison study of IT and traditional DTT when teaching children with ASD expressive use of color adjectives, Miranda-Linne and Melin (1992) found that children in their study initially learned the target skills faster in DTT. Although it took longer for the children to learn the same type of skills in IT, the skills they learned in IT showed increased spontaneous usage and better maintenance and generalization than skills learned in DTT (Miranda-Linne and

Melin 1992). Lydon et al. (2011) also found superior generalization of pretend play skills taught with PRT when compared to a course of video modeling, further supporting the notion that naturalistic behavioral approaches may be ideal for enhancing generalization.

Combining interventions to maximize their strengths can be a very effective teaching strategy for children with ASD (Ingersoll 2010b). Jones et al. (2006) combined DTT and PRT techniques to teach acquisition and generalization of joint attention skills to preschool children with ASD. They found combined benefits of increased joint attention behaviors in addition to collateral effects on expressive language and other social-communicative behaviors. Ingersoll (2011) compared the effects of a responsive interaction intervention, MT, and a combined MT-responsive interaction intervention on expressive language levels of preschoolers with ASD. Responsive interaction is based on the developmental literature and focuses on modeling language and providing expansions. In Ingersoll's study, MT led to more requests and overall prompted language than the responsive interaction intervention. In turn, the responsive interaction intervention led to more comments than MT. The combined MT-responsive interaction intervention yielded the benefits of both interventions (Ingersoll 2011).

Another promising way to maximize intervention outcome is to tailor intervention programs based on individual child characteristics (Schreibman and Anderson 2001). Although many children with ASD benefit from naturalistic behavioral approaches to intervention, there are some children who do not make the expected gains. For example, Ingersoll (2011) found some evidence to support that children with lower-language levels in her study were more likely to benefit from MT whereas children with higher-language levels were more likely to benefit from the responsive interaction intervention. Kok et al. (2002) also found support for individualizing interventions based on child variables and/or the skills targeted in treatment. They increased communication and play skills in some preschool children with ASD using traditional structured teaching and IT methods. The children in their study showed different outcomes based on the intervention received for the target skills and their verbal and cognitive functioning at intake. Children who had higher verbal and cognitive skills in their study yielded more improvements in their play skills during IT and greater increases in their communication skills during the traditional structured teaching (Kok et al. 2002).

Variability in treatment outcome is noted for all forms of behavioral (and other) interventions (Kaiser et al. 1992; Kok et al. 2002; Schreibman 2005; Sherer and Schreibman 2005). Differential response to treatment has long intrigued researchers and therefore searching for child variables that predict outcome has become an important focus of much of the research in the intervention field over the last 15 years (Bristol et al. 1996; Gabriels et al. 2001; Sigman 1998; Weiss 1999). Sherer and Schreibman (2005) identified a predictive profile for young children with ASD that is specific to PRT. The Predictive PRT Profile Assessment (PPPA) was developed using archival data gathered from years of research examining PRT efficacy. They identified five behaviors that predicted how well a child would respond to PRT: toy contact, approach, avoidance, verbal self-stimulation, and nonverbal self-stimulation. Based on each child's incidence of these behaviors, the authors were able to predict which children would make substantial gains during a course of PRT (responders) and those who would not (nonresponders). To validate the findings of their archival data analysis they conducted a prospective study in which three children who were classified as nonresponders and three children who were classified as responders participated. All six children received an intensive course of PRT. The children with the "responder" profile made significant gains in language, play, and social skills after treatment. In contrast, the children with the "nonresponders" profile did poorly, rarely making even limited gains in any skill area. A further examination of the use of the PPPA with a different set of children with ASD showed that the predictive PRT profile is likely to be specific to PRT. Children who were nonresponders to PRT in their study had a variable response to DTT (Schreibman et al. 2009). By identifying children early as treatment responders or treatment nonresponders to specific interventions, researchers can save time and resources as well as develop further appropriate treatment techniques for children with ASD.

Jobin et al. (2012) recently conducted a study to simultaneously evaluate the effects of combining treatments and the role of child variables in maximizing intervention outcome. Specifically, they examined whether particular developmental areas or skill domains may be best addressed using DTT or PRT. In addition, they also determined whether child variables might influence whether or not specific children are more likely to benefit from DTT or PRT. Preliminary results indicate the most effective treatment for individual children in their study was indeed based on the skill domain targeted and child variables such as early learning patterns, avoidance behavior, and rate of learning. Their combined findings indicate that a hybrid intervention package that is assigned based on the skills targeted and individual child variables may be best for children with ASD in order to maximize treatment outcome (Jobin et al. 2012).

Other than these few studies about promising treatment combinations and the development of innovative techniques to individualize intervention programs for children with ASD, there is very limited research on either practice. More controlled research is needed as there is some evidence to suggest that intervention providers working in applied settings with children with ASD are already combining traditional structured teaching (e.g., DTT) and naturalistic behavioral approaches (e.g., PRT; Stahmer 2007; Stahmer et al. 2005). Since there are no available evidence-based practice guidelines for combining or assigning interventions based on child needs, it is likely that children with ASD are receiving interventions rather arbitrarily. Ingersoll (2010b) suggests that cooperation across disciplines is necessary in order to effectively combine interventions for children with ASD. She encourages intervention researchers to systematically study the similarities and differences in interventions such as naturalistic behavioral approaches and approaches from the developmental literature in order to maximize intervention program effectiveness. Only by methodically examining these treatment similarities and differences and how they interact with child intervention needs can we truly understand the ideal combinations for each individual child with ASD.

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Picture Activity Schedules

14

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Keywords

Picture activity schedules · Scripts and script fading · Manual guidance · Prompt fading

By the age of two, typical children imitate others' behavior, but children with autism spectrum disorder (ASD) may imitate only if someone models a response and says, "Do this." Typical 4-year-olds use scissors, but many youngsters with ASD do so only if invited, "Let's cut." Most 5-year-olds speak in sentences and greet familiar people, but their peers with autism may initiate greetings only if told, "Say, 'Hi.'" These examples illustrate the prompt dependence that is characteristic of so many young children with ASD. How did they become so dependent upon verbal prompts from others?

It is possible that discrete trial teaching contributes to prompt dependence, although little research has examined this possibility. In discrete trial teaching, a trial begins when an instructor asks a question or gives an instruction. Then the child responds correctly or incorrectly or does not respond and the instructor delivers or does not deliver a reward. If the response is correct, the learner uses or consumes the reward, and then waits for the next trial to begin. The response sequence is: *Wait for an instruction,* respond, and use or consume a reward. In this paradigm, waiting for an instruction or prompt is repeatedly rewarded, and behavior other than quiet waiting delays the next trial and the next reward (McClannahan and Krantz 1997).

Although discrete trial instruction may create prompt dependence, it is nevertheless an important part of contemporary science-based practice, and is essential to the development of verbal imitation, direction following, academic, and many other skills. However, activity schedules can help to promote the independent use of skills and are therefore a critical addition to discrete trial teaching.

Research Foundations

In the 1970s and 1980s, some researchers examined the use of pictorial cues (pictures, photographs, line drawings) to enable children and adults with developmental disabilities to engage in self-care, home living, and vocational tasks (e.g., Connis 1979; Frank et al. 1985; Martin et al. 1982; Robinson-Wilson et al. 1977; Sowers et al. 1980; Sowers et al. 1985; Thineson and Bryan 1981; Wacker and Berg

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1983, 1984; Wacker et al. 1985). These investigations typically included packages of prompting procedures, such as verbal instruction, modeling, manual guidance, gestures, and self-recording.

Beginning in the nineties, investigations using photographic activity schedules demonstrated that this intervention strategy increased social initiations, on-task, and on-schedule behavior, and decreased disruptive behavior in children with autism (Banda and Grimmett 2008). The first of these, a 1993 study by MacDuff, Krantz, and McClannahan, was conducted in a group home, and was designed to evaluate the effects of a two-component teaching package—photographs, and manual guidance that was delivered from behind the learners and subsequently faded to light touches and then withdrawn. Each of the four boys with autism, ages 9–14, used an activity schedule that contained six photographs depicting homework and leisure activities. The intervention procedures produced sustained on-task behavior, and the boys' skills generalized to a new sequence of photographs and to new photographs. Pierce and Schreibman (1994) also used color photographs, placed in albums, to teach daily living skills (e.g., setting the table, making lunch, and getting dressed) to three boys with autism, ages six, eight, and nine. Their study included a package of procedures that included verbal prompts, modeling, pointing, and gesturing, after which the therapist's presence was gradually faded.

An investigation by Bryan and Gast (2000) replicated and extended the MacDuff et al. (1993) study. The participants were four younger children with autism (ages 7–9 years), who were served in a resource room and in a regular classroom with special supports. Their picture activity schedules displayed four line drawings that cued them to use literacy-based activities (e.g., handwriting worksheets, books on tape). The effectiveness of graduated guidance was replicated across the four participants and their on-task and on-schedule behavior generalized to novel activity schedules. On a social validity questionnaire, teachers and paraprofessionals agreed that the children became more independent when using picture schedules, and that picture schedules are a useful management tool.

Activity Schedules Decrease Disruptive Behavior

In a study by Krantz et al. (1993), three couples were taught to help their children with autism follow photographic activity schedules that depicted home-living tasks, such as putting away a lunch box, getting a snack, obtaining depicted toys, and finding an interaction partner. During the teaching condition, a trainer used modeling, supervised practice, and feedback to help parents learn to use and fade graduated guidance. The three boys, ages six, seven, and eight, displayed increased on-task and decreased disruptive behavior when their parents taught them to use activity schedules, although disruptive behavior was never a target of intervention.

Similar findings were noted when three students with moderate to severe autism, ages 6, 7, and 12 years, were taught to use photographic activity schedules during recess (Machalicek et al. 2009). Color photographs of playground equipment (e.g., slide, swing, tunnel) were placed in each student's schedule, and matching photographs were attached to the playground equipment. Graduated guidance was used to prompt a boy to remove a picture from his schedule and attach it to a matching photograph in the corresponding play area; then teacher proximity was decreased. If a child left the target play area, he was guided to return to it. After 2 min, the teacher said, "Check your schedule," and guided a student to return to his schedule. The intervention increased appropriate play and decreased challenging behavior such as hand biting, screaming, throwing rocks, hitting, and kicking.

Activity Schedules Increase Engagement and Independent Transitions

In a study conducted in integrated public school classrooms (Hall et al. 1995), aides were taught to decrease verbal prompts and gestures and to use photographic activity schedules and manual guidance. During intervention, there was an increase in independent engagement for all three elementary-age children to whom the aides were assigned. On a post-investigation questionnaire, the paraprofessionals reported that they would repeat the program with other children, and would recommend it to others. They also identified the activity schedules as helpful. Other investigators have also found that picture activity schedules increase on-task behavior (Massey and Wheeler 2000; Morrison et al. 2002).

Line drawings used with two boys with autism, ages 5 and 7 years, were effective in decreasing transition time in home and community settings (Dettmer et al. 2000). In the same vein, research by Cihak and Ayres (2010) and Cihak (2011) showed that both picture activity schedules and video self-modeling activity schedules increased independent transitions at school for four students with ASD, ages 11–13 years.

Activity Schedules Teach Social Interaction

Krantz and McClannahan (1998) used photographic activity schedules as vehicles to teach social initiations. Three boys with autism, ages 4, 4, and 5 years, had previously learned to follow schedules. Although they had small verbal repertoires, they seldom spoke to others, except to mand or respond to questions or instructions. Prior to the study, the youngsters were taught to read the words “Look” and “Watch me” and during the teaching condition, these words, on white note cards, were embedded in their 16-page activity schedules. The script “Watch me” was always displayed above photographs of activities, and the children were manually guided to obtain the depicted materials (e.g., a ball) and then approach the adult recipient of interaction, say the script, and subsequently perform the target activity (e.g., throwing the ball). The script “Look” was always displayed below pictured activities; after completing an activity (e.g., coloring a picture or completing a puzzle) the boys were manually guided to approach the adult and say, “Look” to initiate conversation about a completed product. The adult conversation partner never asked questions or gave directions, but responded to children’s initiations with phrases and short sentences. After manual guidance was faded, scripts were faded by successively cutting away one-third of the cards on which they appeared. After learning to use the scripts, the boys’ unscripted interaction increased, and maintained when a different recipient of interaction was introduced and after scripts were faded, unscripted interaction maintained and generalized to different activities that had never been the topic of teaching.

A subsequent study (Stevenson et al. 2000) examined the social interaction deficits of four boys with autism ages 10–15, who had limited expressive language repertoires and required continuous supervision. The boys had learned to greet others, and to use polite phrases such as “please” and “thank you,” but they rarely engaged in spontaneous conversation, except to make requests. They used photographic activity schedules throughout the school day, and during the study, scripts recorded on magnetic cards were embedded in the participants’ activity schedules among 25 nonsocial activities, such as puzzles and handwriting worksheets. The scripts were represented in the boys’ schedules by identical photographs of a card that could be run through a card reader to play a script. During teaching, an instructor stood behind a participant and used graduated guidance to assist him in approaching a conversation partner (a familiar teacher) and playing a prerecorded statement or question. If he did not say the script, he was guided to play the recorded script again (and again, if necessary). The recipient of interaction responded to the young people with elaborations of their statements, but never asked questions or gave instructions. Scripts were faded in 1–11 sessions, by deleting words from last to first. As scripts were faded, the pictorial stimuli in activity schedules that represented social activities (i.e., the photographs of magnetic cards) were also faded by cutting away portions of the photographs. During maintenance, when no prompts were delivered, the boys’ mean number of unscripted interactions ranged from 21 to 27 per session.

Other investigations used picture cues to teach children to report events of the day (Murdock and Hobbs 2011) and to interact with peers (Betz et al. 2008). In the latter study, three dyads of preschoolers, ages 4 and 5 years, learned to use joint activity schedules to engage in peer interaction. Each schedule book provided four opportunities for peer play; each page showed a picture of a participant at the top, and below it, a picture of the game to be completed. The child whose picture was shown on a page was responsible for reading the script, "Let's play (game)." Scripts were faded from last word to first word, one word at a time until all words were absent. Five of the six youngsters completed script fading and independently initiated to peers.

While some researchers focused on teaching children to initiate interaction with peers, Wichnick et al. (2010b) taught three participants with autism, ages five through seven, to respond to peer initiations. The children used written activity schedules that contained prompts to "share toys with friends." Instructors stood behind the children and used manual guidance to help a child remove a toy from a toy bag, give it to a peer, and emit an initiation (initiations were maintained from a previous study). During teaching, a peer not only initiated and gave another child a toy, but also gave him/her a button-activated voice recorder. Hand-over-hand guidance was used to teach the recipient to play and say the recorded script to the peer initiator. Subsequently, scripts were faded and, in the last fading step, voice recorders were removed. As a result of the script-fading procedure, all three participants showed systematic increases in novel, unscripted responses to peers.

Summary

An excellent review of research on the effects of activity schedules was conducted by Banda and Grimmett (2008). They conducted a computer search using *ERIC* and *PsychInfo,* using the key words *autism, Asperger, activity schedule, picture schedule,* and *photographic schedule*. Subsequently, they included only those studies that reported on participants with autism, involved an activity or picture schedule as an intervention, were data based, and were published in peer-reviewed journals. The 13 studies that met these criteria showed activity schedules to be effective interventions for all 31 participants with ASD.

The results documented the effectiveness of activity schedules in increasing independent on-task and on-schedule behavior, independent transitions, social engagement, play behavior, and daily living skills, as well as decreasing tantrums and disruptive behavior. Further, 5 of the 13 studies included social validation of the interventions, based on responses from teachers, paraprofessionals, and parents.

Activity Schedules: A Framework for Intervention

In this section, we review details of how activity schedules are implemented. For a nonverbal 2-year-old with ASD who has recently entered intervention, a first activity schedule might comprise five color photographs placed in a 5 in. by 7 in. three-ring binder, one photograph per page. Photographs of activities and materials appear on plain backgrounds in order to minimize irrelevant stimuli. The photographs in an initial schedule for a toddler might show play materials such as shapes and shape box and stacking cups; a social activity—for example, getting a toss in the air (the photograph shows a familiar person who will toss the child); a pre-academic activity, such as identical pictures to be matched; and a preferred snack that has been identified via prior reinforcer assessment. Velcro® dots may be placed on the lower right corner of each page to facilitate page turning.

The materials used in the schedule are prominently displayed on a table or shelf that is easily accessible to the child and are arranged in the order in which they will be used. For children who have picture-object correspondence skills, materials such as shape box and stacking cups are placed in transparent plastic boxes, and the boxes and their contents are shown in the photographs in the schedule. For youngsters who do not yet have picture-object correspondence skills, a photograph identical to the photograph in the schedule is mounted on the outside of the plastic tub, to facilitate picture matching. For children who cannot yet match pictures, it is often helpful to place photographs in baseball cardholders and mount them in the album with Velcro® so that a youngster can be manually guided to remove the photograph from the schedule and reattach it beside the matching photograph on the corresponding box of materials.

The primary purpose of this first schedule is not only about content, but perhaps more importantly, about teaching a child the basics of schedule following. The target responses are: Open the schedule book or turn a page, point to a picture, obtain the corresponding items and take them to a desk or work area and complete the task or engage in the depicted activity, return materials to their original location, and return to the schedule and turn a page. These skills are taught with manual guidance. Hand-over-hand guidance is advantageous because, after a few practice sessions, most instructors can determine, for a given response, whether to increase guidance to prevent errors or diminish guidance to promote independence.

Manual guidance is delivered from behind the child, so that the adult does not come between a youngster and her materials. When a child has acquired some correct responses, full manual prompts are faded in the following sequence: (a) graduated guidance; (b) spatial fading (Cooper 1987), or changing the location of manual prompts—for example, from hand to wrist to forearm to elbow to shoulder; (c) shadowing; and (d) decreasing proximity to the learner. Gestures and verbal prompts are never used to teach schedule following because these procedures may create prompt dependence. For the same reason, rewards (edibles, tokens) are always delivered from behind the learner. The instructor may reach from behind to place small bites of a preferred food in the child's mouth, or drop tokens in a cup that is visible to the child. Although the final activity in the schedule (e.g., a snack) is presumably a reward, it is subject to the same procedures as any other activity in the schedule. For example, the youngster turns a page in the schedule book, points to a picture of raisins on a paper plate, obtains the snack and takes it to her desk or play area, consumes it, throws the paper plate in a nearby wastebasket, returns to her schedule, and closes the book. If she has not yet learned to use tokens, she immediately receives a preferred activity or another snack; if she uses tokens, she exchanges them for an item or activity of her choice, from an array of items or photographs.

Although the most-to-least prompt hierarchy described above is designed to minimize errors, they do occur. The error-correction procedure is to return to the previous prompting procedure. If the instructor was using graduated guidance, she returns to full manual guidance; if she was shadowing, she returns to spatial fading, and so on. The prior prompting procedure continues until the child makes one or more correct responses on the schedule component associated with the error; then prompts are again faded. For example, if the teacher is decreasing her proximity to the child and the youngster makes an error when turning a page of the activity schedule, the teacher returns to shadowing and continues that procedure until the learner makes one or more correct page-turning responses, after which she again gradually decreases proximity.

The procedures used to teach activity schedules are grounded in science, but pictorial, written, video, or computer-based schedules are not stand-alone procedures. Further, activity schedules are not intervention strategies to be used during limited times or settings. They are designed to be tools that guide children throughout the day. At best, activity schedules frequently change and expand to reflect users' new skills and they provide a framework for many different types of instruction. "People with autism, like all of us, must learn to learn in a variety of ways: From direct instruction; from incidental teaching; from television, videotape, and computer; from parents, teachers, peers, and employers; and from pictorial, auditory, and textual cues" (Krantz 2000). Applied behavior analysis offers many well-documented intervention procedures for children with ASD and activity schedules can support implementation of these instructional strategies.

Activity Schedules in Early Intervention

After a first schedule is mastered, it is time to re-sequence the photographs, change the order of materials displayed on shelves, and add new photographs and activities. Of course, these next steps are taken sequentially, and only after data on a child's performance show mastery. For many 2- and 3-year-olds with ASD, some next additions to the activity schedule may be motor- and verbal-imitation sessions, learning to point with index finger, scribbling with a crayon, building with blocks, matching identical objects, following simple instructions, and using early childhood computer programs. Some of these activities (e.g., building a four-block tower or using a computer coloring program) will be taught with manual guidance that is faded, so that the youngster ultimately pursues them with minimal or no help. Other activities in the schedule (e.g., direction following, verbal imitation) will be teacher directed. The selection of manual or verbal prompts will be based on the terminal goal. That is, the choice between the use of manual or verbal prompts should be guided by the question: Should the child ultimately pursue the target activity without verbal prompts, or is it appropriate for adults to instruct? For example, typical children use computers, watch videos, and accomplish toilet and dressing tasks without verbal prompts or gestures, but they often receive instruction when learning to talk, to identify objects, to count, and to read.

As activities in the schedule are mastered, they can be used to construct schedules for use at home, at grandparents' homes, and in community settings. Many of the skills acquired in one setting will readily transfer to another, where they will be maintained. In our setting, it is not unusual for 2-year-olds to learn to independently follow first schedules within 2 or 3 months of program enrollment. Their schedules continue to expand, and most 3- and 4-year-olds follow schedules that encompass the five–and-a-half-hour preschool day. A portion of a typical photographic schedule for a 4-year-old is shown in Table 14.1.

The 4-year-old's entire day is cued by photographs that set the occasion for many different instructional strategies across many different domains. Instructional strategies are selected based on identification of the final stimulus controls. For example, verbal-imitation skills are taught during discrete-trial instruction, because we want children to learn to benefit from others' language models. Using computer,dressing, toothbrushing, and playing with construction toys should not be controlled by adults' directions, but by location, time of day, and the presence of the materials; these skill sets are taught with manual guidance that is faded.

Some of the activities in the schedule are teacher directed (e.g., story) and some are child initiated (e.g., incidental teaching of object labels). The schedule includes adult–child interaction and peer interaction, social play and independent play, one-to-one and group instruction, and computer or video-based instruction. The content of an activity schedule is determined by each child's skills and skill deficits, and schedule modifications are based on the data on a youngster's performance. The goal is to teach children to be active participants in learning activities. Photographic cues help them learn to independently obtain materials and initiate instructional activities, put materials away, and begin next activities.

After mastering some early activity schedules and learning to manage their own materials, many children begin to take responsibility for their belongings and restore order to their environments. During manual guidance, children are assisted in picking up items in their schedules that are dropped or spilled, returning materials to their original locations, throwing paper plates and napkins in wastebaskets, and similar responses. When guidance is faded, most youngsters continue to display these skills. For example, if wiping the lunch table was depicted in the activity schedule, they continue to wipe the lunch table when that photograph is no longer present. When pictures are faded, they put used tissues and paper towels in wastebaskets, pick up small pieces of paper that fall on the floor when cutting with scissors, pick up items they drop, and man-

Table 14.1 A photographic activity schedule for a 4-year-old with ASD

Photograph	Target schedule-following response(s)	Instructional strategy
Instructor 1	Remove script that is attached to door frame; greet instructor 1	Scripts and script fading; manual guidance to obtain script (and if necessary, to point to script)
Locker	Hang coat, put lunchbox in locker, close locker door	Manual guidance
Classroom door	Walk to classroom	Manual guidance
Instructor 2	Get script attached to classroom door; greet instructor 2	Scripts and script fading, manual guidance
Bin that contains a computer disk	Put disk in computer; complete puzzle on computer, return disk to bin	Manual guidance
Bin with color identification materials. (Button-activated recorder is attached to schedule page)	Obtain bin containing materials; press button to play script, “Ready,” or “Let’s learn colors” and imitate script	Scripts and script fading; discrete trial
Teacher on rug with book, reading to other children	Go to rug and sit down	Discrete trial (ask questions about the story)
Bin with counting materials. (Button-activated recorder is attached to schedule page)	Obtain counting materials, go to desk, activate recorder to play and imitate script, “Let’s count”	Scripts and script fading, discrete trial
Cover of a notebook that shows parent at home in living room	Take notebook to desk. Obtain and complete familiar activities in a schedule that will soon be used at home	Script fading, fading manual guidance (shadowing and fading proximity to student)
Bin with materials for verbal imitation. (Button-activated recorder is attached to schedule page.)	Take bin to desk. Play the recorded script, “Ready,” or “Let’s talk” and say script to instructor	Scripts and script fading, discrete trial
Two photos on one page: Toy shelves and kitchen timer with colored buttons	Go to toy shelves. Take timer to activity schedule. Press timer buttons that match colored buttons on photograph. Play with toys until timer rings. Press button to stop timer and return to schedule	Manual guidance
Binder with picture of peer on cover	Obtain binder, go to peer’s desk, open binder, complete depicted peer modeling and peer imitation activities	Manual guidance, scripts and script-fading procedures, modeling
Preferred toys on a high shelf, beyond child’s reach	Go to shelf and reach for or request toy	Incidental teaching of object labels
Untied shoes (button-activated recorder is attached to schedule page.)	Untie shoes, play and say the script, “Please help me”	Scripts and script fading, manual guidance and backward chaining to teach shoe tying
Learner sitting in front of TV, touching toes	Go to exercise area. Wait for video to begin. Imitate exercises modeled	Video modeling
Toilet or urinal	Go to bathroom. Pull pants and underwear down. Urinate in toilet. Pull up underwear and pants	Manual guidance
Hands under faucet in bathroom sin*k*	Wash and dry hands, return to classroom	Manual guidance
Notebook with picture on cover that displays classmates at lunch	Obtain lunchtime notebook, go to lunch room, open lunchtime schedule	Manual guidance
Peers in lunch room with attached voice recorder	Play script, greet peers	Scripts and script fading, manual guidance
Lunch box	Go to locker, obtain lunch box, return to lunch room	Manual guidance
Open lunch box	Remove contents of lunch box and place on table	Manual guidance
Student eating	Takes bites of lunch	Manual guidance

Table 14.1 (continued)

Photograph	Target schedule-following response(s)	Instructional strategy
Student drinking	Takes drink of juice	Manual guidance
Voice recorder	Activate voice recorder, say script to peer	Manual guidance, scripts and script fading

age their own schedules. It is not unusual to observe an accomplished schedule follower examining next schedule pages and then returning to the correct page to do the pictured activity, much as we review our to-do lists before pursuing our next tasks.

Activity Schedules Prevent or Diminish Errors

For children with ASD, errors often evoke disruptive behavior, with the result that instructional time is lost. Further, once errors are made, they are often repeated. The antecedent prompting procedure, manual guidance, faded to graduated guidance, spatial fading, shadowing, and decreased proximity to the learner, is a strategy for decreasing errors. In addition, the error-correction procedure—returning to the prior fading step until the learner makes several correct responses—helps to prevent repeated errors.

Although the most-to-least prompt sequence minimizes errors, error analyses are important. For example, is a particular photograph in the schedule associated with a high error rate? If we scrutinize those photographs, we sometimes note background stimuli (e.g., candy, a hat and coat) that have unintended salience for the learner. Do certain play materials (e.g., a top, a drum) depicted in the schedule evoke stereotypy? Error analysis helps to identify and prevent such problems. These error reduction procedures and error analyses, combined with a continuous schedule of reinforcement that gradually becomes intermittent, enable many young children to complete lengthy response chains that do not include high-rate vocal or motor stereotypy.

Activity Schedules Address Key Repertoires Associated with ASD

Parents of children with ASD often report their resistance to changes in routine. For example, the children may cry at birthday parties, attempt to isolate when grandparents visit, tantrum when a parent takes a different route to the grocery store, resist wearing new clothing or sampling new foods, or cry when a new baby brother or sister cries. Activity schedules can help children learn to adapt to changes in their environments and their usual activities.

Resequencing the photographs in children’s schedules, substituting original photographs for pictures taken from a different perspective, deleting photographs of previously mastered activities and adding new photographs and novel activities, lengthening activity schedules, and changing interaction partners—all of these procedures help youngsters learn to tolerate change. For children who have acquired basic schedule-following skills, it may be helpful to add a picture (for example, a photograph of a gift bag) that indicates a “surprise.” Initially, when a child arrives at the “surprise” picture, the instructor may produce the gift bag that contains a preferred snack. On future appearances of the “surprise” picture, the instructor may provide favorite toys or activities. Next, the “surprise” photograph is followed by a 1 min “party,” during which the instructor wears a party hat and produces a party plate containing a preferred snack. On a subsequent occasion, the “surprise” in the activity schedule is followed by a brief visit from an unfamiliar person, who delivers a preferred toy and then departs. Of course, the ratio of rewards to unanticipated events is adjusted to help preschoolers succeed when confronted with changes in routine, with the goal of gradually increasing the proportion of unanticipated change events that the child can tolerate without engaging in challenging behavior.

Sometimes, the activity schedule itself is sufficient to remediate resistance to change. A preschooler who was a skilled schedule follower, but who refused to sample new foods, was given an activity schedule that included pictures of a red bowl, a blue bowl, and a yellow bowl. Before each lunch, the contents of the bowls—a preferred food, a non-preferred food, and tokens—were non-systematically rotated across bowls. Pictures of the bowls controlled either eating a bite of a preferred or non-preferred food or taking a token. Tokens were frequently exchanged for preferred snacks. This young boy, who previously refused many foods, learned to sample new foods because the activity schedule controlled responding.

Similarly, an activity schedule proved useful for a 5-year-old with ASD who screamed and ran away whenever his infant brother cried. To address this problem, several pictures in his schedule showed his mother holding the baby while he brought her a diaper. When he encountered these pictures, a staff member who was holding a doll in a blanket said, “Tommy, could you please bring us a diaper?” and another instructor manually guided him to obtain and deliver the diaper, after which the pretend mother responded by thanking him and giving him a preferred toy or snack that was immediately used or consumed. When this response sequence was dependably exhibited, the photograph in the schedule was accompanied by a low-volume audiotape of a baby crying, and the boy continued to be rewarded for approaching with the diaper. The volume of the audiotape was gradually increased, until it was at or above the loudness of the infant’s crying, and the youngster continued to display the target responses in the early intervention setting, after which prompts were faded, the pictorial cues were added to his home activity schedule, and he assisted his mother and infant sibling at home.

Activity Schedules Promote Family Participation

After young children have learned to follow a first photographic activity schedule, it is time to begin preparations for the use of schedules at home. Although the first brief picture schedule may be taught in a quiet room, schedules are then introduced in busy classrooms, where there are many distractions. The goal is to help young children remain engaged when they follow schedules at home, where there may be disturbances such as ringing telephones, noisy siblings, and high-volume televisions. It may also be important to rotate instructors, in order to program generalization across adults.

Initially, parents are invited to visit the early intervention program, observe their child’s schedule following, collect data on the youngster’s performance, and then learn to use and fade manual guidance and deliver rewards. When a youngster consistently displays the desired responses in the treatment setting with a parent as prompter, the activity schedule is introduced at home. During this process, a staff member from the intervention program models the procedures, observes parents’ implementation, and provides feedback (McClannahan and Krantz 2001).

When new activities are introduced, they are typically taught first in the intervention setting and then transferred to home. Family activities and parents’ preferences are important in selecting next activities. Parents who have a special interest in music may want a young child to learn to hum or sing a song or pick out a few notes on the piano. Families who enjoy biking may want a young boy or girl to learn to ride a tricycle and later, a bike with training wheels. Parents who enjoy regular television watching may want a youngster to learn to play with toys on a rug near the sofa while family members watch a favorite program. Others may want a child to learn to play catch or kick a soccer ball. Activity schedules that acknowledge family preferences are more likely to be implemented at home.

Parents who are proficient with schedules learn to improvise and adjust schedules according to momentary needs and family members’ commitments. For example, if a quick trip to the grocery store is necessary, or a sibling needs a ride to an after-school event, a photograph of a car ride is inserted in a youngster’s schedule. If a young child appears tired, a picture of a nap is added. If an unexpected visitor arrives, independent play activities are added to a boy's schedule. If a girl is off task while using the computer, the parent abbreviates the activity. If a youngster engages in stereotypy while moving from room to room, his parents may temporarily add sit-down activities to his schedule.

Over time, many children's mastery of schedule-guided activities at home makes it possible to remove photographs from home schedules and create new schedules to be used at aunts and uncles' or grandparents' homes, during unexpected visits from relatives or friends, during car rides, in the barbershop or hair salon, or in doctors' and dentists' offices. Parents sometimes package these activity schedules and the accompanying materials in bags or backpacks, so that they are immediately available, even on short notice. Many children, ages 3–6 years, use activity schedules from the time they arrive home from the intervention setting until bedtime.

Activity Schedules Promote Choice and Independence

After a young child acquires a basic schedule-following repertoire, it is time to teach choice. Instruction often begins by presenting photographs of two preferred items on the last page of the schedule. Using graduated guidance, the instructor lightly holds the child's hand above the page until he reaches for one of the pictures. Then he is guided to remove the picture he selected and obtain the corresponding item. If a learner does not reach for a picture after a few seconds, he is guided to take one, thus excluding the other. Most children quickly learn to make a choice. When a child regularly chooses one of two pictures without prompts, three choices are depicted on the schedule page. Subsequently, choices of rewards are presented on a nearby "choice board" or in a separate three-ring binder, and the number of items and activities is gradually expanded, until young children may make choices from a field of ten or more photographic stimuli.

Children are also taught to select the order of learning activities. Initially, pictures of two tasks appear on a page, and a child might select either counting or verbal imitation. Again, the number of choices gradually increases, until a preschooler may determine the sequence of nearly all of the activities in her schedule.

Learners often have separate schedules that teach play or gross motor skills. These schedules may contain no photographs; Velcro© dots are centered on the otherwise blank pages. The number of accompanying photographs, on a nearby choice board or in a bin, is greater than the number of pages in the schedule book. Children not only learn to sequence these photographs and activities, but also to exclude certain photographs of toys or activities. Ultimately, the blank pages in the book are replaced by single photographs of play or exercise areas, which appear in youngsters' daily schedules; then they independently make selections of play or exercise activities.

Incorporating choice has a variety of benefits. For example, research with children and adults with ASD indicates that engagement is higher in choice versus no choice conditions (Ulke-Kurkcuoglu and Kircaali-Iftar 2010; Watanabe and Sturmey 2003), and that opportunity to choose task sequence is associated with higher on-task scores, more rapid task completion, and decreased problem behavior (Smeltzer et al. 2009).

As noted earlier, the most-to-least prompt hierarchy was selected for the purpose of promoting independent engagement and minimizing prompt dependence. But in our experience, the final fading step—decreasing adult proximity to a child—is the step least often implemented. Perhaps teachers and parents are fearful of separating from 2–6-year-old children with ASD. But for children in this age group, decreased proximity may mean stepping behind a bookcase or room divider, or moving just outside a play area or classroom, so that the adult is no longer visible to the child. If the goal is to enable children to remain productively engaged in the absence of immediate supervision, adults must fade proximity.

In a study by Pelios et al. (2003), independent work skills were established in three boys with autism, ages 5, 9, and 9 years, who had a history of remaining on task when instructors were present, but engaged in stereotypy in their absence.

Throughout the investigation, the boys followed activity schedules that displayed on alternate pages either a single, previously learned word (e.g., "math," "coloring"), or a penny, which was self-delivered; at the end of the session, pennies were exchanged for preferred items. Manual prompts were faded to graduated guidance, spatial fading, shadowing, and then proximity decreased until the teacher was outside the room. Subsequently, the teacher entered the classroom for 2 s every 2 min, then 3 min, then randomly every 2–5 min and then every 3–5 min. During treatment, if a boy took a penny without completing a task, the teacher manually guided him to return the token and follow the schedule, and if stereotypy or other off-task behavior occurred for 3 s or more, the teacher removed all previously earned coins and manually guided the participant to begin the schedule again. The on-task and on-schedule behavior of all three boys generalized to a novel setting and to novel materials, in the absence of adult supervision. This investigation underlines the independence that can be achieved by children with ASD when adults' proximity is faded and supervision is unpredictable.

At first glance, it may seem unusual and unnecessary to fade adults' proximity and promote the independent behavior of very young children. Staff members in early intervention programs sometimes resist moving beyond a young child's line of sight or stepping outside the classroom, perhaps because it may appear that they are doing nothing. But parents are often aware of the difficulties of continuous supervision. At home, parents must attend to other children, prepare meals, answer telephone calls and e-mails, receive guests, and pursue housekeeping tasks, and these tasks are difficult to complete if a young child with autism has not learned to remain appropriately engaged, at least for a few minutes. Teaching young children to use photographic activity schedules and deliver their own tokens not only promotes independent performance, but also helps to reduce parents' response cost.

The Evolution of Activity Schedules

As noted earlier, activity schedules are gradually extended from a few photographs to many photographs that guide youngsters through the day, including time spent in the intervention program as well as time spent at home. As new activities are added, it is important to evaluate their age appropriateness. A 3-year-old with ASD who identifies alphabet letters and reads a few sight words may receive a good deal of positive attention, but a 6-year-old who plays with stacking cups and teething rings will be viewed quite differently by others. For children with severe disabilities, activities can (and should) be modified to reflect chronological age. For example, a 5-year-old who cannot yet match pictures and corresponding objects can learn to match identical objects on a computer, and can be taught to follow an activity schedule that enables him to match photographs in the schedule with photographs mounted on bins that contain the corresponding materials.

Typically, activity schedules lengthen because children master longer response chains. After response sequences such as washing hands, brushing teeth, or setting the table have been mastered, single photographs in the main schedule may depict other schedule books with pictures of hand washing, toothbrushing, or table setting on the covers. Learners then obtain sub-schedules, go to the relevant locations, complete the depicted responses, and return to their main schedules.

When a child's schedule is lengthy and has been frequently practiced, it is often possible to delete cues that are no longer needed. For example, at snack time, when a boy correctly obtains napkin, cup, and paper plate without looking at the corresponding photographs, it is time to remove those cues and replace them with a single photograph of paper plate, napkin, and cup, near a bottle of juice and cookies. If he then makes errors, prompting resumes and in some cases, photographs may be temporarily replaced. But it is essential to remove pictures that children no longer reference, because failure to do so may teach them that they need not use their schedules.

Activities change and schedules are updated as children acquire new skills. The discrete-trial verbal imitation of phonemes depicted in a 2-year-old's schedule later becomes imitation of words, and then imitation of phrases and short sentences. Photographs of dressing skills, such as putting on shoes, are replaced by photographs of shoe tying and pictures that show steps in getting dressed.

Similarly, social activities depicted in children's schedules become increasingly complex. A schedule for a nonverbal 2-year-old may include a picture of a child standing in front of an adult with arms raised to request a toss in the air. Subsequently, the photograph may be accompanied by a magnetic card or button-activated voice recorder that plays the sound/uh/, an approximation of the word "up." Later, as speech is acquired, recorded scripts may include "up," "want up," "I want up," and "I want up, please" (McClannahan and Krantz 2005). Next, scripted conversation moves beyond mands to more typical interaction with teachers and peers (Krantz and McClannahan 1993; Wichnick et al. 2010a).

As activity schedules evolve to reflect children's developing repertoires, an issue of primary importance is making them similar to others' to-do lists, daily planners, appointment books, and calendars. Often, a first step in this direction is teaching children to read sight words that represent activities in their schedules. In our experience, some young children who use the carefully programed Edmark Reading Program (1992) to learn to read sight words may readily learn to use written activity schedules when sight words are superimposed on photographs for some time, after which photographic backgrounds are abruptly removed. Other children, however, do not benefit from these procedures.

Birkan et al. (2007) used superimposition and background fading to teach a young boy with ASD to read 15 target words that represented the activities in his physical education schedule. The 6-year-old was selected as a participant because he had used the Edmark Reading Program for 5 months, but had learned only 16 sight words.

Prior to the study, he was taught to label the 15 photographs in his schedule (e.g., slide, swing, basketball, Pogo stick). During intervention, Adobe Photo Shop© was used to superimpose the target words on photographs of corresponding activities; then portions of the photographs were gradually removed, until only the text remained. After background fading was completed, the boy correctly read 14 of the 15 target words in his schedule, and his reading skills transferred to different text size and color. During the 24 days of the study, he learned 14 sight words.

Miguel et al. (2009) used match-to-sample conditional discrimination training to teach two preschoolers with ASD to select pictures and printed words when the names of these stimuli were dictated. After they learned to match dictated words to pictures and dictated words to printed words, stimulus control transferred from pictures to printed words. Although neither of the boys could consistently follow a textual activity schedule during baseline, they could do so after training. Other investigators have shown that written lists that remain available mediate delays and promote correct responding (Stromer et al. 1998).

Activity schedules not only evolve from pictures to text, but also to video applications and stimuli presented on desktop and pocket computers. Rehfeldt et al. (2004) described the use of PowerPoint® software to create schedules that included photographs, sounds, text, and videos, and that contained both close-ended (or completion-based), and open-ended (or time-based) activities. It is evident when completion-based activities are over—the last piece has been placed in the puzzle, the worksheet is finished, or all dressing tasks have been completed. In contrast, open-ended activities (such as reading books, playing with wheel toys, listening to music) have no obvious conclusion and therefore end with a signal indicating that it is time to put materials away and return to the schedule. When children use schedule books, they learn to set digital kitchen timers by matching color photographs of timers with colored buttons on the timers. When using PowerPoint® schedules, a slide displays a clock that is programed to chime after a designated amount of time has elapsed.

Several investigations have compared the effectiveness of picture schedules and video modeling schedules. Cihak and Ayres (2010) found that all four participants with ASD began transitions more independently after learning to use visual (pictorial and video-modeling) schedules. Two participants reached criteria more quickly with picture schedules, one met criteria faster with a video schedule, and the performance of the fourth student was similar on both schedules.

A 2010 comparison of picture and video cues to teach daily living skills (Van Laarhoven et al. 2010) found that video produced more correct responses with fewer prompts. However, a comparison of a photographic schedule presented in a three-ring binder and the same schedule presented on a personal digital assistant (PDA) found no difference in the performance of students with ASD; the two formats generated similar levels of on-task and task completion (Decker et al. (2003). Cihak (2011) noted that if the two types of intervention achieve similar results, teachers may make choices based upon the time, skills, and resources required for one type of schedule versus another.

Pocket computers or PDAs are widely used, readily portable, and are becoming more affordable. Mechling et al. (2009) used a Hewlett Packard iPAQ Pocket PC® to teach cooking skills to three high school students with ASD. Photographs, video, and verbal prompts were presented, and it was therefore unclear which of these was related to task completion. For some learners, verbal prompts such as, "Get the skillet out of the cabinet" may be difficult to fade. The authors observed that some students may have difficulty moving from one screen to the next and using a stylus or touch screen.

In an extensive review of activity schedules and computer technology for children with ASD (Stromer et al. 2006), the authors cited the importance of computers in generating precise programing of photos, text, sound, voice, timers, and video, as well as their value as potential reinforcers.

Use of computer-based activity schedules will be partially determined by the resources available to intervention programs and parents. In addition, adoption of this technology should be determined by observational data on each child's skills and preferences. Many typical young children use iPods®, iPads®, and similar computer technology to play and to learn. Activity schedules in notebooks may draw unwanted attention in community settings; schedules on pocket computers are less visible and offer rewards such as video games and music. Such schedules enable children with ASD to approximate the behavior of their nonhandicapped peers.

Self-Management

Self-management has been defined as the "systematic application of behavior change strategies that result in the desired modification of one's own behavior" (Heward 1987). The author also noted that this is a functional definition; if behavior change is not observed, self-management has not occurred.

Activity schedules include several components of self-management, such as teaching children to make choices of rewards and activities, independently change activities, monitor and evaluate their own performance, and deliver their own rewards (Stromer et al. 2006). Many investigations have documented that children with ASD can use activity schedules to independently change activities and remain engaged in the absence of treatment providers (cf. Hall et al. 1995; MacDuff et al. 1993; Schreibman and Pierce 1994).

If data show that pages in a schedule book are turned or an iPod is advanced to subsequent pictures only after depicted activities are completed, we may consider that children are engaging in self-monitoring. In practice, many children self-deliver rewards that are depicted in their schedules. Final pages often show preferred snacks, toys, or activities (riding a rocking horse or tricycle, playing a video game) that are based on prior reinforcer assessments, and that are self-delivered.

As children become more accomplished schedule followers, tokens or coins may be attached to the center of every other schedule page, or to the bottom of each schedule page, and self-delivered. A youngster completes a depicted task, removes a token, and places it on a nearby token board before turning the page. When all of the activities in the schedule are completed, or when the schedule displays a picture of a token board with all tokens attached, the learner exchanges the tokens for a reward of his choice. Pelios et al. (2003) taught two boys with ASD to self-administer pennies and exchange them at the end of sessions for preferred items or activities. If a participant was off task for 3 s or more, all acquired pennies were removed and the boy was manually guided to begin the schedule again.

At the Princeton Child Development Institute (PCDI), we used activity schedules to teach self-monitoring (McClannahan et al. 2009). The three youths with ASD, ages 14, 15, and 18, were experienced schedule users, and at the time of the study, all used written schedules. A nonconcurrent multiple baseline across students was used to assess interobserver agreement between instructor–student dyads. During baseline and teaching, the activity used was making apple muffins. The activities used on pre- and posttests were assembling metal frames for hanging files and printing digital photographs and the activity schedule for follow-up was sending a fax. None of these activities was previously taught, and the teens' past performance suggested that there would be ample opportunities to score both correct and incorrect responses.

The dependent variable was interobserver agreement between instructor–student pairs. During data collection, the instructor did not talk to a student, but used graduated guidance when necessary to help him perform tasks. During teaching, after both members of the dyad marked their data sheets (i.e., activity schedules), the instructor placed her schedule adjacent to the student's schedule and compared scores. Agreements were followed by behavior-descriptive praise and token delivery; disagreements were followed by corrective feedback and token removal. After two consecutive sessions in which student and instructor achieved 100 % interobserver agreement, feedback was delayed to the end of the activity. The student's data sheet was collected but not reviewed with him. If interobserver agreement was 80 % or better, the instructor delivered praise and tokens; if agreement was less than 80 %, the instructor said, "We disagreed. It's time for (next activity)."

During baseline and pretests of assembling hanging file frames and printing digital photos, all three youths had 0 % interobserver agreement with the instructor. On posttests conducted during maintenance, their interobserver scores ranged from 80 to 100 %, and on a follow-up assessment 7–10 weeks after maintenance ended, all three students obtained 100 % interobserver agreement with the instructor.

The participants in this study, who had lengthy experience with photographic and written activity schedules, were successful in self-monitoring their own schedule-following skills. However, we have observed much younger children who, after observing their instructors scoring data sheets, made similar marks on their written activity schedules. In some cases, their responses matched those of their instructors, although the latter were taught to keep data sheets covered. Perhaps these informal marks are an indicator of readiness to engage in self-monitoring.

Maintenance

Activity schedules are designed to maintain previously mastered skills. For example, 12 photographs that were originally derived from a task analysis of taking a bath and putting on pajamas are eventually subsumed by a single photograph of a young child near the bathtub; bathing skills are maintained by that cue until it is no longer necessary. Six photographs that guided a youngster to remain engaged with toys during a ride to the grocery store are replaced by a photograph of the bag that contains the toys. Ten photographs that show the steps in obtaining an after-school snack are later replaced by a picture of milk and cookies. And multiple pictures that enable a preschooler to engage in play with a peer are removed from the schedule, which then displays a photograph of the peer and the game.

Data from the clinic document the maintenance of skills mastered in previous activity schedules as children leave the early intervention program and enter regular or special education, but there is insufficient research on maintenance. MacDuff et al. (1993) demonstrated that when four boys with autism were taught to follow activity schedules that contained six homework and leisure activities, all of them displayed high on-task and on-schedule performance during 23–64 maintenance sessions. Because a multiple-baseline design was used, a teacher was present during maintenance to prompt the youth entering the treatment condition, but the boys in maintenance received no prompts. Krantz et al. (1993) reported that after three sets of parents were taught to use activity schedules at home, disruptive behavior (which was never a target for training) maintained at low levels for 10 months for two of the boys and for 2.5 months for the third child.

Pierce and Schreibman (1994) noted the importance of reporting the presence or absence of adults during experimental conditions, and suggested that adults' proximity may contribute to learners' success. During a final training phase of their study, the therapist's presence was faded. Initially, the therapist intermittently made a statement such as, "I'll be back in a minute," and left the clinic room for 20 s; absence time was gradually increased. This procedure was not effective for one participant; for him, adult presence was gradually faded until the therapist was no longer in view. In a 2-month follow-up probe with a picture book, all three children completed the daily living tasks, albeit with some performance variability.

In the Bryan and Gast study (2000), four 7- and 8-year-olds in a resource classroom were taught to use picture activity schedules, using manual guidance that was faded. During two Book-Only maintenance conditions—a total of eight sessions during which only the schedule book was present but no manual prompts were delivered—the experimenter initially gave a general instruction and then some individual task instructions. Although no additional prompts were delivered, on-task and on-schedule behavior was verbally praised. In these conditions, participants' percentage of steps completed on schedule ranged from 90 to 100 %, and percentage of momentary time samples scored as on task ranged from 98 to 100 %. The presence of the experimenter and the delivery of praise statements make it difficult to evaluate these maintenance data.

In the Pelios et al. (2003) study cited earlier, the teacher randomly checked on a student once per maintenance session, on the first to fourteenth minute, and was present in the room for no longer than 2 s. Percentages on task and on schedule during maintenance were high (range = 97 to 100 %) for two of the three participants. There were eight maintenance data points for one learner, two for another, and none for the third, because the school year ended.

It is not unusual to note that investigations of activity schedules contain either no maintenance data or minimal data; for example, 3–5 maintenance data points that immediately follow intervention (Watanabe and Sturmey 2003), or two follow-up observations at 3 and 5 months (O'Reilly et al. 2005).

Odom et al. (2003) analyzed articles that support the effectiveness of practices for young children with ASD. Articles included in their review met the following criteria: They were published in peer-reviewed journals; they used single-subject designs that demonstrated a functional relationship between the independent and dependent variables; at least half of the participants in the study were identified as having autism, ASD, or a pervasive developmental disorder not otherwise specified; and at least 50 % of the children were younger than 6 years. Thirty-seven studies were included in their review, and only 13 (35 %) included maintenance data. It is clear that maintenance requires more attention, not only with regard to activity schedules, but also apropos of other intervention strategies.

In practice, the ongoing revision of activity schedules in response to data on children's skill acquisition, promotes maintenance. A picture activity schedule that originally showed many photographs of dressing (putting on underpants, undershirt, socks, shirt, pants, and shoes) eventually displays a photograph of a child in his bedroom getting dressed, and all of these responses are maintained by a single cue. Similarly, a series of photographs may include going to a locker, obtaining a lunchbox, going to the lunch room, obtaining a paper plate, obtaining a napkin, opening the lunchbox, and putting the contents on the plate. Later, when the data showed that this response sequence is mastered, all of the pictures are replaced by a single photograph of a child in the lunchroom with her lunch on a plate. Each mastered response sequence is maintained by a photograph or word in an activity schedule, until that single cue is replaced by other stimuli that evoke our own behavior, such as time of day, clocks, the presence of clothing or food, and the activities of other people.

Cues that promote maintenance evolve from lengthy sequences of photographs to single photographs; from photographs to one or two words presented on single pages of three-ring binders; and from words in notebooks to words in typed or handwritten lists, planners, and pocket computers. These cues maintain target repertoires until those response chains come under the control of the stimuli that evoke our own repertoires. Of course, these dependable outcomes occur only if we carefully manage antecedent stimuli (in particular, manual guidance that is faded), consequent stimuli (rewards that are based on prior reinforcer assessment and children's in vivo choices), and data on learners' performance.

Generalization

There is ample evidence that activity schedules, taught with manual guidance and a most-to-least prompt fading sequence, promote generalized responding (McClannahan and Krantz 2010). As noted earlier, schedule-following skills transfer to different sequences of pictures, to different pictures, and from pictures to text.

Generalization Across Settings

Activity schedules are portable; the stimuli remain constant across settings; and photographs, videos, and text are continuously available and can be referenced as needed. Research has demonstrated transfer of on-task repertoires across rooms at school (Pelios et al. 2003) and across home and school settings (Pierce and Schreibman 1994). Decreases in transition time were also found to generalize across home and community settings (Dettmer et al. 2000).

In the early intervention program, cross-setting generalization can be actively programed. For example, a 2-year-old may follow a photographic activity schedule that takes him to the housekeeping area to play with dishes and cooking utensils, to the gym to imitate exercises presented on video, to the dining room to eat lunch, to the locker area to learn to button his coat, to his desk in a classroom to practice verbal-imitation skills, and to an opposite corner of the classroom to interact with a peer. He spends little time sitting in a chair—he is busy obtaining materials, completing depicted activities, putting materials away, and moving from room to room (using and fading manual guidance helps most children quickly learn, not only to manage the materials depicted in their schedules, but also to manage their schedule books and tokens, to take them from room to room, and to keep them near at hand.).

The parent training sequence described earlier—inviting parents to first observe and learn to use schedules in the intervention setting and later, to implement them at home with a staff member's support—also promotes generalization across settings. At home, there is no isolated "therapy room." A 3-year-old's schedule may contain a picture of the bathroom and pictures relevant to using the toilet and washing her hands, a picture of the kitchen and a sequence of photographs that enable her to obtain a snack, a picture of the backyard and her tricycle, and a picture of a computer in the living room that she will use to do a preschool coloring program. Later, as she masters these activities, the schedule will change and she will pursue different activities in these and other rooms of her home.

As previously noted, schedules are also useful in achieving children's sustained engagement in community settings such as grocery stores, churches or temples, relatives' homes, public transportation, and family vehicles. A young child's car schedule may display a cover photo of the family car, and if the youngster is not yet verbal, the first page may contain a photograph of the first destination (e.g., post office), followed by a photograph of an activity such as playing a game on an iPad. If there are several destinations, photographs such as dry cleaner and grocery store alternate with pictures of activities, such as listening to music or looking at books. Tokens mounted on each page are removed when an activity is completed. When all tokens are earned, the child selects a reward from several pictures of preferred items or activities.

Several investigators have reported the favorable effects of activity schedules on transitions across activities (Hall et al. 1995; MacDuff et al. 1993; Massey and Wheeler 2000; Schmit et al. 2000) but insufficient attention has been given to one of the most important transitions—from intervention setting to regular preschool or school. Activity schedules build repertoires that support children's success in next placements. Many researchers have noted that activity schedules produce sustained engagement and decrease disruptive behavior. In addition, because activity schedules program delivery of rewards for task completion while gradually increasing time and response effort, they teach children to respond to temporally delayed contingencies—an important prerequisite for entering public education. As cues become less specific, a schedule that once displayed many component photographs is condensed, and displays single photographs, or a few words, such as "story time," "reading," and "counting," so that small picture schedules or to-do lists can be used in public settings without drawing undue attention. Further, the use of scripts and script-fading procedures promotes generative language. All of these features of activity schedules support children's successful transitions to public schools (Krantz and McClannahan 1999).

Generalization Across People

In their review of single-subject design studies of intervention for young children with autism, Odom et al. (2003) found only 6 of 37 studies (16 %) that assessed generalization across people. Banda and Grimmett (2008) reviewed 13 studies that used activity schedules; they found six studies that reported generalization of schedule-following skills across settings, but noted only one that reported generalization across persons. Krantz and McClannahan (1998) embedded textual cues ("Look" and "Watch me") in three preschoolers' activity schedules. After learning to use the scripts, verbal elaborations and novel verbal productions increased, and generalized to a different recipient of interaction.

In practice, activity schedules are used to program generalization of social interaction skills (McClannahan and Krantz 2005). A first photographic schedule for a nonverbal child may depict him approaching and orienting toward a partner and may include a very short script ("up," "tickle," "hug") played on a button-activated voice recorder. As a youngster develops verbal-imitation skills, scripts embedded in the activity schedule are not only played on a voice recorder, but also imitated—a boy or girl points to a picture of a conversation partner, removes the voice recorder from the schedule, approaches the adult, and plays and imitates (or approximates) the script. Adults make brief, enthusiastic responses and attempt to use words that the child understands.

When first scripts are introduced, children learn the new repertoire when interacting with the instructor or parent who is the usual interaction partner. But soon, the cues in the activity schedule are programed to occur across people. A child who has learned to activate a voice recorder and imitate the word "hug" may find photographs that depict hugs from mother, father, and older siblings. For a youngster with more language, pictures of peers pulling a wagon, riding a tricycle, or running a race may be interspersed in the activity schedule, setting the occasion for him to approach and use scripts to initiate play with several different children.

Activity schedules and recorded or written scripts are used to teach children to recruit attention. After completing a Lego® construction, a photo in a child's schedule cues him to show the completed model to an instructor and say a script such as "Look" or "See," after which the adult responds with interest. Other pictures and scripts help him approach different adults and display other accomplishments, such as coloring or shoe tying. Initially, teachers and parents are nearby, but as a youngster becomes a more accomplished schedule follower and user of scripts, adults fade manual guidance and gradually fade proximity, so that the child learns to persist in finding an interaction partner, even though adults are out of sight.

Generalization Across Tasks

Research shows that activity schedules promote skill transfer across activities and materials never associated with training (Bryan and Gast 2000; MacDuff et al. 1993; Pelios et al. 2003). Pierce and Schreibman (1994) found that training time decreased across pictures and tasks and Weiberg-Aurdal (undated) reported that when a developmentally disabled adult was taught to follow lengthy schedules to do laundry, make waffles, and make pasta, each successive task was more quickly acquired with fewer prompts from the trainer.

In a study conducted at the PCDI during a 6-month period (McClannahan et al. 2009), eight students with ASD, ages 12–17 years, were pretested on every new instructional program that used an activity schedule. All of the young people were experienced schedule followers, and all used written schedules. Prior to the beginning of each new intervention program, a participant was given a pretest without an activity schedule and a pretest with a schedule. The same instructions were given in each pair of pretests (e.g., "Please make the bed," or "Please make a turkey sandwich"), after which no prompts were delivered. On 30 of 32 new programs (94%) introduced, students achieved higher scores when schedules were present than when they were absent, and the magnitude of difference ranged from 3 to 75% more tasks correctly completed. Their schedule-following skills transferred to new, never-taught schedules and to many different activities, including food preparation, personal hygiene, and housekeeping tasks. Further, skill generalization was documented for students with severe as well as moderate disabilities.

Training and Dissemination

Science-based intervention programs such as activity schedules are not sufficient; organizational and administrative variables also determine treatment effectiveness (McClannahan and Krantz 1993). The PCDI model of training, quality control, and dissemination is described below as one example of a systematic approach to ensuring the highest quality of service. At PCDI, the accountability system is based on yoked outcomes for children, staff members, their trainers, the trainers' mentors, and program administrators.

A trainer/consultant is assigned to each staff member; the consultant provides ongoing, hands-on training and data-based feedback, based on a training protocol that is also the evaluation protocol. The staff member and consultant agree on when they will engage in a "pre-evaluation"—that is, a practice evaluation. Subsequently, training continues until both parties agree that the teacher or therapist is prepared for the annual evaluation, conducted by a consultant who is not the instructor's primary trainer.

Intervention staff members are recognized as successful when data on the progress of learners for whom they are responsible document positive behavior change. Trainers are acknowledged as successful when (a) they pass their evaluations, conducted by program administrators or other accomplished behavior analysts; (b) their trainees display target skills during their performance evaluations; and (c) data document favorable treatment outcomes for the learners served by the trainees. Finally, program administrators experience success only when data document desired outcomes for learners, instructors, and the instructors' mentors. This system of linked outcomes is important to effective program operation.

In addition, each year impartial professionals with expertise in applied behavior analysis and ASD are invited to review the intervention programs provided to toddlers, preschool and school-age children, and adults, using a protocol developed and validated at PCDI. Reviewers assess program documentation: They determine whether a program includes, at minimum, an objective response definition; a description of a measurement procedure; a description of the intervention procedure; and a graph or other type of data summary.

The external reviewers also score whether positive behavior change has occurred; whether, based on professional ethics and knowledge of the literature of the field, the intervention procedures are appropriate; whether written parent or guardian consent has been obtained within the past 364 days, or since program revision; whether at least four interobserver agreement measures have been obtained on a target response or repertoire during the past year; and whether the program contains assessment of skill generalization.

Finally, broad-scale consumer evaluation is conducted annually. Staff members evaluate their colleagues, trainers and evaluators, program administrators, and the intervention program; and parents, members of referring agencies, and members of the nonprofit board of trustees evaluate the program and program administration. Increasingly, consumer evaluation is conducted, not with paper-and-pencil questionnaires, but online. Consumers' responses are tabulated and reported by persons not affiliated with the intervention program. When all annual evaluation activities are completed and summarized, they are submitted to the governing board and disseminated in an annual report.

PCDI's technology dissemination program began in response to a severe shortage of effective intervention. Parents and parent organizations in the USA and other countries request support with program development. Before entering into a relationship with a potential new agency, the institute thoroughly investigates organizational variables, board structure and function, personnel resources, and commitment to science-based intervention. If a formal relationship develops, PCDI participates in the selection of an executive director (a person with a doctoral degree in behavior analysis) who subsequently completes a one-year residency at the institute. Some applicants do not survive this first round of assessment, and no final agreement is reached.

But if the applicant agency meets criteria and an agreement is formalized, PCDI initiates comprehensive program development services that include providing the PCDI curriculum, as well as model policy manuals and administrative systems, and assistance with the selection of staff, facilities, equipment, and instructional materials. After the new program opens, senior PCDI professionals are continuously available for telephone consultation, and weekly on-site consultation on administrative procedures, staff training, children's intervention programs, and the development of evaluation systems. When a staff performance evaluation system is in place, institute representatives train evaluators and assist with evaluations. PCDI also helps new agencies establish consumer and program evaluation systems, participates in program evaluation, and monitors the data from all evaluation activities.

New agencies are recognized as successful in adopting the PCDI intervention model only if all evaluation systems are implemented, and only if the annual data indicate that the program meets specific standards. Most developing programs receive technical assistance over a period of several years, but levels of service diminish as an agency moves toward full staffing and full enrollment, and achieves documented positive outcomes for children.

Presently, five intervention programs are based on the systems developed at PCDI. They are: New York Child Learning Institute, College Point, New York; Institute for Educational Achievement, New Milford, New Jersey; Somerset Hills Learning Institute, Bedminster, NJ; Institute for Child Development, Gdansk, Poland; and TOHUM Otizm Vakfi School, Istanbul, Turkey. All of the children served in these programs use activity schedules.

Summary

This chapter began with a discussion of prompt dependence. Magee and Ellis (2006) noted that insufficient attention has been given to this problem. They wrote:

> Dependence may result from an undesirable set of contingencies wherein assisted performance is reinforced. Consequently, the behavior on which error-correction feedback/prompt delivery is con-

> tingent may increase or be maintained, possibly blocking transfer of control to the relevant stimulus. (p. 206)

In our investigations of activity schedules, we began with Foxx's (1982) definition of a prompt as "an auxiliary discriminative stimulus that is presented to cue the student to perform a specified behavior" (p. 81). Subsequently, when confronted with the problem of prompt dependence, we turned to a functional definition of a prompt as an auxiliary discriminative stimulus that precedes a specified response and results in its occurrence. Manual guidance is that kind of prompt; when skillfully used, it almost uniformly produces the behavior of interest and later, a well-defined prompt-fading sequence also yields correct responses. Of course, these outcomes occur only if children have the benefit of well-trained staff members.

Activity schedules are no different from other behavioral intervention strategies; they require intervention agents who are skillful prompters and prompt faders and excellent behavior shapers. Careful task analyses, reinforcer assessments, and data-based decision making are also necessary. Stromer et al. (2006) observed that activity schedules are suitable venues for translating basic research into practice because "the study and use of activity schedules are informed by laboratory analyses of conditional discrimination learning, stimulus and response classes, naming relations, and remembering" (p. 14).

A common misconception is that activity schedules should be used for short periods of time to keep children busy, and teaching should occur at other times. To the contrary, activity schedules are most effective when used throughout a child's day. Well-designed schedules for young children teach social interaction, play skills, daily living, and pre-academic and academic skills in multiple contexts—in teacher-directed and child-initiated activities; in video modeling, computer, and paper-and-pencil activities; in one-to-one and group activities; in preschool, home, and community settings; and with different people and at different times.

Planning for maintenance includes teaching children to manage their own schedules—to obtain them; to turn pages; to make choices that result in adding or removing photographs and activities; to take them to many different home, school, and community settings; and to keep them at hand. Such planning also includes replacing multiple cues with single photographs or words.

Preparation for the long term also requires making an activity schedule as naturalistic as possible, within the parameters of a child's current repertoire. A series of photographs posted on a wall, a set of pictures managed by a teacher, or stimuli presented on a desktop computer may temporarily serve as a schedule, but these formats soon become less viable because children must learn to enter many different settings and interact with many different people. Schedules in three-ring binders, daytimers, pocket computers, and iPads are not only more portable, but are also more typical of others' to-do lists, memos, and reminder systems.

> Baer (1997) wrote:
>
> One meaning of independence is freedom from instructions, prompts, and demands; another is the ability to do what we will when we want…We can conceptualize independence as a behavior-environment arrangement we can confer on our students and clients. (p. 269)

He also noted that activity schedules can change intervention settings from places where others follow someone around giving instructions and prompts, to places where a person does things without such supervision. Perhaps one of the most important things we can do for young children with autism is to build repertoires that support independence and choice.

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Use of Visual Supports with Young Children with Autism Spectrum Disorders

15

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Keywords

Visual supports · Visual schedules · Visual cues

Visual supports are a commonly used intervention strategy for individuals on the autism spectrum. Broadly defined as "tools presented visually that support an individual as he or she moves through the…day" (Hume (2008)). visual supports take on a number of forms and functions. These include, but are not limited to, photographs, icons, written words, objects, furniture arrangement, schedules, maps, labels, organizational systems, timelines, and scripts (Hume (2008)). and have proven effective in both increasing prosocial behavior (i.e., task engagement, independent performance) and decreasing maladaptive behavior (i.e., self-injurious behavior) across age ranges and settings. Visual supports are recognized as an evidence-based practice by the National Professional Development Center (NPDC) (Odom et al. (2010). Evidence-based practices) and schedules, one example of a visual support, are deemed an established treatment by the National Autism Center's National Standards Project (National Autism Center's National Standards Project (NSP) (2009). However, the application of visual supports, the efficacy of their application, as well as the appropriateness of their use with very young children with autism spectrum disorder (ASD) remains less understood and less studied than their application to the school-age population. The purpose of this chapter is to describe the rationale for the use of visual supports in the broader early intervention field, the application to early intervention settings with young children with ASD, as well as the researchbase supporting their use. Specific supports identified in the literature will be highlighted, including environmental supports, visual schedules, visual cues, scripts, and video-based instruction, along with recommendations for future use and study. Please note that the use of picture activity schedules is covered extensively in its own chapter in this volume.

Definition of Visual Supports

A number of terms are used in the literature to describe and define visual supports, including visually cued instruction (Quill 1995), visual teaching aids (Rao and Gaige 2006), visual representations (Meada et al. 2011), and visual approaches (Devlin 2009). Each refers to the use

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of a concrete cue, such as an object, drawing, or written word, paired with or instead of a verbal cue to provide information about a routine or expectation and/or to support skill demonstration. Though in use in the autism field for almost 3 decades, visual supports gained popularity, as well as the increased attention and interest of researchers and practitioners, following the publication of Temple Grandin's book *Thinking in Pictures and Other Reports From My Life* in 1995. Grandin, a well-known professor and public speaker with autism, provided a glimpse into information processing for individuals with ASD and revealed the importance of visual images to her ability to understand abstract concepts (Grandin 1995). This work, in combination with a wave of brain research that indicates some individuals with ASD have relative strengths in visual detail processing and visual search skills in comparison to typically developing individuals (Kaldy et al. 2011), has encouraged the use of visual supports, now one of the most frequently used intervention strategies in both research and practice (National Standards Project 2009; Stahmer et al. 2005).

Visual supports can employ simple techniques, such as presenting a photograph representing the next activity to a child with ASD (Schmidt et al. 2000), as well as more complex techniques, such as presenting a video clip of an upcoming event for individuals to view before it occurs (Schreibman et al. 2000). Beyond providing information about upcoming activities, routines, or behavioral expectations, visual cues can serve as a scaffold or support in the demonstration of communication skills (i.e., using text and pictures to increase verbal greetings, Reichow and Sabornie 2009), social skills (i.e., using a picture to initiate social interactions, Johnston et al. 2003), adaptive behavior (i.e., using a Social Story with pictures to increase appropriate responding during circle time, Schneider and Goldstein 2010), and academic skills (i.e., using picture dictionaries and product samples to increase task completion, Mavropoulou et al. 2011).

Application of Visual Supports to Young Children

Visual support for early learning has been effective for teaching young children with a range of special needs, particularly children with speech/language impairments, social-communication difficulties, and/or poor understanding (Bochner and Jones 2003). Through the use of visual supports, early intervention professionals can enhance their teaching of specific skills across all developmental domains, manage behavior, and promote independence (Wellington and Stackhouse 2011).

Indeed, the Division for Early Childhood (DEC) of the Council for Exceptional Children specifically addresses the visual needs of young children in *Promoting Positive Outcomes for Children with Disabilities: Recommendations for Curriculum, Assessment, and Program Evaluation* (DEC 2007). This document highlights the importance of providing multiple means of representation and expression within the curriculum and through assessment and progress monitoring with the use of visual supports and other strategies. Instructional activities should therefore be designed to ensure that proper accommodations, such as visual supports, are put in place to meet children's individual learning needs (Sandall et al. 2002, 2005).

Research evidence does show that children with and without disabilities benefit from visual supports. In fact, research has identified a picture-superiority effect where pictures are better remembered than words regardless of age and intellectual functioning (Cherry et al. 2002; Seitz 1997; Whitehouse et al. 2006). Therefore, in keeping with recommended practices, the use of visual supports in early intervention can help promote optimal learning and development (DEC 2007; Sandall et al. 2002).

Application of Visual Supports to Young Children with ASD

Given the characteristics of ASD, the use of visual supports for young children with ASD is particularly important (Hodgdon 1999). The core features of ASD include difficulties with social interactions, communication, and having restricted interests or repetitive behaviors. Visual supports can address all of these areas by making abstract concepts more concrete, facilitating communication, and increasing independence (Hodgdon 1999; Peeters 1997). Furthermore, visual approaches are consistent with supporting underlying cognitive features of ASD: enhanced perceptual functioning, weak central coherence, and executive dysfunction.

Enhanced perceptual functioning Research indicates that individuals with ASD have enhanced perceptual functioning when engaged in visual processing (Bertone et al. 2005; Dakin and Frith 2005; Mottron et al. 2006; Samson et al. 2012). Through brain imaging studies and superior performance on visual tasks, individuals with ASD show enhanced visual mental imagery or “visual thinking” as compared to typically developing individuals. Instead of words, individuals with ASD have described their reasoning processes comprising a series of images or rather that they “think in pictures” when engaged in problem-solving behaviors (Grandin 1995; Kunda and Goel 2011). Therefore, visual strategies can be utilized to capitalize on this strength.

Weak central coherence Individuals with ASD may exhibit a bias towards local processing rather than global processing (Happé and Frith 2006). Several studies have shown superior performance on tasks that are reliant on local processing versus those that rely on global processing of stimuli, thus supporting the theory that individuals with ASD may have more difficulty extracting the overall meaning or “big picture” while attending to specific details instead (Grinter et al. 2010; Ploog et al. 2010). While many of the tasks used to test local processing tend to be visual (e.g., embedded figures, block design, visual search), individuals with ASD also perform well on several nonvisual local tasks (e.g., pitch and melody perception; Happé and Frith 2011). While visual supports tend to be more global in nature as they represent chunks of information, their nontransient attributes do allow for children with ASD to take more time in processing information that is visually supported (Johnston et al. 2003).

Executive Dysfunction Research suggests that individuals with ASD have impairments in executive functions impacting activities such as planning and organizing (Hill 2004). However, assessment of executive functions tend to rely heavily on language abilities and verbal working memory which may negatively limit the ability of individuals with ASD to excel on such tasks (Baldo et al. 2005; Russell et al. 1999). Further research is required to examine the types of tasks used to measure executive function and the level of verbal encoding of rules required to complete those tasks (Kunda and Goel 2011). In the meantime, specific attention is required to ensure that visual supports are provided for individuals with ASD to complete activities requiring executive functioning.

Research-Base

Visual supports are considered a *focused intervention,* a strategy or procedure designed to be utilized for a relatively brief period with the aim of producing specific behavioral and developmental changes related to targeted behaviors or skills (Odom et al. 2010). They are intended to be used as one component of comprehensive programming for individuals with ASD. Two national centers, the NPDC on ASD and the National Autism Center’s National Standards project (NSP), have recently conducted independent and complementary reviews of focused intervention practices for individuals with ASDs. These national centers were charged with reviewing the intervention research literature, identifying standards for determining research quality evaluating research designs, categorizing evidence-based practices, and disseminating that information to practitioners and families. In 2007, the Office of Special Education Programs in the US Department of Education funded the NPDC to promote the use of EBPs in programs for infants, children, and youth with ASDs and their families. An initial activity of this center has been to identify

EBPs. In addition, the NSP, an initiative of the National Autism Center, has recently completed an exhaustive review of the strength of evidence for psychosocial and behavioral interventions for individuals with ASDs (NSP 2009). These two efforts are the most current, comprehensive, evaluative reviews of the literature on focused intervention practices for learners with ASDs (Hume and Odom 2011).

Visual supports meet the criteria as an evidence-based practice for young children with ASD, as determined by the NPDC. Several other practices which include visual components that will be addressed in this or other chapters (i.e., Picture Exchange Communication System, social narratives, video modeling, and structured work systems) are also considered evidence based. In addition, schedules, a widely used visual support, are considered an Established practice by the NSP (2009). Both centers have recognized visual supports/schedules as effective with preschool age children with ASD, yet visual supports have not been identified as evidence based with the 0–2 population. Both centers are currently conducting updates to their literature review and evidence for efficacy with the toddler population which may be indicated in the more recent literature.

One consideration, however, is the broad definition of visual supports used by the NPDC, which includes maps, labels, timelines, graphic organizers, visual boundaries, and a number of other examples. While these can certainly be categorized as a visual support, which is deemed evidence based, there may not be enough evidence for each of these supports to independently be considered an evidence-based practice. For example, a thorough review of the literature revealed no evidence that supported the use of labeling classroom materials or furniture with photos to increase specific child behaviors (e.g., independence in cleaning up, use of a variety of materials, increased engagement). However, labels are included in NPDC's definition of visual supports and environmental labels are often recommended for children with ASD (Ganz 2007). This should not preclude the use of these practices, as practitioner experience, family preferences, individual child characteristics, professional judgment, and the evidence base for individual visual supports established outside of the autism population should also assist in guiding the selection of specific visual supports. It is important to keep in mind, however, that *all* visual supports have not been proven effective for use with children with ASD, and fewer still with young children on the spectrum. Further discussion around these issues continues below.

Considerations Around Developmentally Appropriate Practice

Intervention differs for young children and older children because it must be developmentally appropriate (Sandall et al. 2005) and therefore target different skills and use different techniques for targeting those skills. Visual supports are particularly useful as they can be easily individualized for and promote development in young children with ASD (Meadan et al. 2011) and can be used to supplement current programing. For young children with ASD, visual supports may be particularly appropriate. For instance, they can attract and hold a child's attention (Rao and Gagie 2006) and are fairly nonintrusive (Meadan et al. 2011). Additionally, they provide a concrete form of representation which is developmentally appropriate for young children who are not yet able to process more abstract concepts (Ginsburg and Opper 1988). However, choosing appropriate visual supports depends on the child's developmental level as well as the child's sociocultural context (Bredekamp and Copple 1997). Decisions about visual supports should be made by a team which includes the practitioners as well as the family of the young child with ASD (Sandall et al. 2005).

One particular area of visual supports is quickly emerging. The use of technology is increasingly used to provide visual support for young children with ASD (e.g., computers, handheld devices) and should follow the same developmental guidelines as other interventions (Haugland 2005; Izumi-Taylor and Blake 2010). Technological visual supports are especially attractive to young children with ASD and can allow children to use at their own pace (Izumi-Taylor and Blake). Additionally, procedures for determining devices should follow best practices for obtaining assistive technology which includes borrowing a device for a trial period, seeking funding, and providing adequate training for the child, family, and professionals (Judge 1998).

Specific Visual Supports

A number of individual visual supports are described below, along with the literature base supporting their use with individuals with ASD, and more specifically with young children with ASD. The supports are organized by category—environmental supports, visual supports used to establish expectations, visual cues, and video-based visual supports—and individual visual supports within those categories are italicized for quicker and easier identification by readers. This chapter is not exhaustive, as visual supports are often components of other focused interventions (e.g., a token board is a visual support when used with a token system for reinforcement) and will be discussed in other relevant chapters. In addition, visual supports are often components of comprehensive treatment models serving young children with ASD, such as Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH, Mesibov et al. 2005) and Learning Experiences and Alternative Programs for Preschoolers and their Parents (LEAP, Strain and Bovey 2011). Studies on these and other comprehensive treatment models utilizing visual supports are not included in this review. For further review of several models and their components, see Odom et al. 2010.

Visual Supports to Organize Learning Environments

The use of an organized intervention setting when working with young children with disabilities, including those with ASD, is a widely recommended and long-studied practice (Bailey and Wolrey 1984; Nordquist and Twardosz 1990; Sandall et al. 2005). An environment that provides functional cues about the activities that will occur in each space as well as the behavioral expectations for those activities is more likely to promote and sustain student engagement in young children (Norquist and Twardoz 1990). The DEC recommends providing clearly defined learning centers in early childhood settings and the use of visual cues to assist in segmenting the space (Sandall et al. 2005). In addition, the Early Childhood Environmental Rating Scale (ECERS), a widely used quality rating scale for early intervention environments, recommends barriers to separate quiet and noisy activities and space arrangements which discourage rough play or running (Harms and Clifford 1980). The literature suggests that an organized environment is key for young children with ASD, as several learning characteristics of young children with ASD, including distractibility and difficulty in processing environmental stimuli (Siegel 1999), can be supported through a carefully arranged intervention space. However, many of the recommendations in the autism literature related to an organized environment come from the well-established literature on this topic related to young children with and without disabilities, rather than children with ASD specifically (Bailey et al. 1983a, b; McWilliam et al. 1985)

Visual supports play a significant role in organizing the environment and providing clarity for young children in early childhood settings, as they provide cues to young children about what activity will be occurring and what behavioral expectation is required in each activity space. DEC recommends the use of *colored area rugs, vinyl flooring, or colored masking tape* to distinguish one activity area from another, as well as *low pieces of furniture* to visually and physically define learning centers (Sandall et al. 2005). Visual supports are widely recommended in the literature to segment space in early learning environments for young children with ASD. However, much of the literature cited when making these recommendations is from conceptual writings, practical pieces, and research reviews, rather than recent efficacy or effectiveness studies (e.g., Heflin and Alberto 2001; Iovannone et al. 2003).

Three studies directly examine the effects of an organized physical space, in conjunction with the use of visual supports, on the behavior of students with ASD (Duker and Rasing 1989; Hirasawa et al. 2009; Nordquist et al. 1991). Duker and Rasing found that providing visual boundaries for students (i.e., *covering materials with sheet*s that were not to be accessed or attended to during instructional periods) reduced self-stimulatory behavior and increased on-task behavior in two adolescents with autism. Similarly, Hirasaw, Fujiwara, and Yamane found that *rearranging low furniture and materials,* which served as a physical and visual boundary for a student and reduced staff attention to inappropriate behavior, reduced self-injurious behavior in an adolescent with autism. In the only study including young children with ASD, Nordquist et al. (1991) studied the impact of an intervention package, including *room arrangement* which uses furniture as a visual cue or support, on adult and child behavior. Positive effects were documented in adult behavior, including an increase in adult smiles and affectionate words as a result of the room arrangement specifically.

Visual Supports Used to Establish Expectations

Visual supports can be used to concretely set the expectations for children during activities. These visual supports explain or depict how an activity/task should be completed and/or the behavioral expectations for the child using pictures, objects, or written words. They are provided before and/or during activities to support children in successfully engaging in or completing activities. Within the broad category of establishing expectations, several specific techniques exist, including visual instructions, structured work tasks, scripts, social narratives, and power cards.

Visual Schedules Visual schedules are a type of visual support that allows young children with autism to "see" their upcoming events or activities through the use of objects, photographs, icons/line drawings, written words, or any combination of the listed formats (Mesibov et al. 2005). Visual schedules can be used for several purposes, but have historically been used to provide support for transitions between locations or activity periods, essentially serving as a between-activity support (i.e., move from location to location across the classroom, Dooley et al. 2001). In contrast, activity schedules, as described in the previous chapter, were historically used to support individuals in the completion of a series of steps or tasks or during one activity period (i. e., complete a series of activities during a free-time period, MacDuff et al. 1993; complete the steps of getting dressed, Pierce and Schreibman 1994), thus serving as a within-activity support. In the past two decades, however, the terms visual schedule and activity schedule have become interchangeable in the literature and in practice and are used to both support transitions between activities (e.g., moving from circle time to the bathroom) and to assist in the performance of a series of steps, tasks, or activities more independently (e.g., completing the steps of washing hands once in the bathroom). Thus, the rationale and research base supporting the use of visual schedules with young children with ASD is discussed in the previous chapter describing activity schedules.

Visual Instructions Visual supports have proven effective in supporting academic instruction for individuals with ASD, though the research for young children is limited. This is likely due to the emphasis on curriculum areas outside of academics for young children with ASD such as play, social, and communication skills. However, several of the visual supports used to increase participation and engagement with elementary aged students are likely applicable to early intervention and early childhood curriculum/settings. These include interactive two- and three-dimensional visuals during storybook reading (Carnahan et al. 2009), and product samples and picture dictionaries during completion of play-based and preacademic tasks (Mavropoulou et al. 2011). These studies and visual supports will be briefly summarized, as they include several supports that are applicable to the 3–5-year-old population. However, the youngest children in these studies were age six and further research is required to ensure effectiveness with younger children. The growing body of research investigating the use of various graphic organizers, such as Story Maps (Stringfield et al. 2011) to support the development of more complex academic skills, as well as the use of visuals to enhance self- management in academic settings is beyond the scope of this review, as they are most often implemented with school-age children.

Several types of visual instructions were provided to two 7-year-old boys with autism to increase independent activity completion during playtime (Mavropoulou et al. 2011). These included a product sample (sample of what the task or activity will look like when completed), a picture dictionary, a jig (two- or three-dimensional visual cues outlining how an activity is assembled), and color coding, and when in use the visual instructions supported on-task behavior and a reduction in adult prompting for one student. These visual instructions were applied to play materials such as puzzles, picture matching cards, and Legos, which are similar to those found in many early childhood settings, which may increase the applicability of these visual supports to young children with ASD.

Similarly applicable to the early childhood setting are the visual instructions and supports examined in Carnahan et al.'s study (2009) with six children with ASD, ages 6–11. In a study of student engagement and responding during group story time, researchers studied the effects of two- and three-dimensional interactive story pieces, such as: pictures of relevant items that could be removed from the pages, small apples that could be picked from the page and a basket to place them in, colored cotton balls to be used as a snowman's nose. For example, in the baseline condition the students were asked to respond to teacher questions with only verbal prompts and the storybook pages ("Where is the red hat?" and student would point to the red hat on the teacher's book page), while in the intervention condition, students had access to visuals to interact with and to support the verbal instruction ("Where is the snowman's nose?" and students could remove a cotton ball nose that was attached to the page). The addition of visual interactive materials/instructions increased engagement and responding for three of the students.

Structured Work Systems A work system is a visually based organizational system that provides individuals with visual information about what to do. Work systems are an element of structured teaching developed by Division TEACCH and they visually communicate at least four pieces of information to the individuals: (1) The tasks or activity the individual is supposed to do, (2) How much work/how many tasks to complete *or* how long the activity will take, (3) How the individual knows he/she is finished (progress towards goal), and (4) What to do when he/she is finished (Hume and Reynolds 2010). Information in a work system is presented visually to students based on the developmental level of the child and can range from pictures or objects for those who are more concrete learners to written lists for individuals with strong reading and comprehension skills.

Work systems are similar to activity schedules in that they provide a visual sequence of activities or steps of an activity to complete, however they differ in several ways. First, visual information in the work system is often presented in a more concrete format than typically described in the activity schedule literature, as the actual tasks to be completed may be placed in individual containers on shelves to the individual's left, rather than in a photo sequence. Next, once tasks are completed they are typically placed in a designated location, often called a finished box or finished shelf, located to the right of the individual, encouraging a left to right work pattern. Last, visual information representing the activity that will take place after the series of tasks are completed is present for the individual to view as he/she is completing the tasks within the work system. This activity may be purposefully selected as a preferred/reinforcing activity, or may be simply the next activity in the individual's day (Mesibov et al. 2005). Work systems have primarily been used as a time/space for mastered skills to be practiced independently, similar to a fluency building period (Bennett et al. 2011; Hume and Odom 2007;

Mavropoulou et al. 2011). More recently, however, the work system has been used to support skill acquisition (Hume et al. 2012), yet further research is required to support this application.

Structured work systems are an evidence-based practice per the NPDC, and are included in the Schedules category per the NSP (referred to as workstations). Work systems have been studied both as an element of a broader TEACCH-based model (e.g. Ozonoff and Cathcart 1998) as well as an individual component apart from the model (e.g., Hume and Odom 2007). Several recent studies have examined the use of work systems with preschool and elementary aged students and have found similar positive results in increasing on-task behavior while simultaneously decreasing adult support (Bennett et al. 2011; Hume and Odom 2007; Mavropoulou et al. 2011). Hume and Odom introduced a work system to two boys with ASD, ages six and seven, during free play sessions in an effort to increase their appropriate play and the number of play materials used. A withdrawal design indicated an increase in play behavior and number of play materials accessed, along with a decrease in adult prompting. In a replication of this study with three preschool age students, Bennett et al. introduced a work system in an inclusive classroom to support student engagement and task completion during an independent work and playtime (e.g., completing puzzles, ring stackers, matching game). Positive effects were observed for all three students and included a reduction in both escape and stereotypic behavior. Finally, in a similar replication with two 7-year-old students, Mavropoulou et al. studied the effects of the work system in combination with the use of visual instructions (described more specifically below). The work system was beneficial for one of the students in increasing on-task behavior and decreasing adult support.

Scripts Scripts are created phrases taught to children in order to provide them the language needed to participate in conversations. Scripts are often taught through modeling, role-playing, prompting and/or the use of reinforcement (Ganz and Flores 2010). In addition, scripts generally include a script-fading procedure to increase spontaneous use of language in natural settings (e.g., Sarokoff et al. 2001). Scripts have specifically been shown to be especially effective in improving social and communication skills in children with ASD (Krantz and McClannahan 1998) and are most appropriate for children who have some verbal skills, as opposed to those who are preverbal (Ganz and Flores 2010). Much of the research on scripts has been with school-aged children or adolescents and include written scripts (e.g., Brown et al. 2008; Ganz et al. 2008; Krantz and McClannahan 1993; Sarokoff et al. 2001). For example, Ganz et al.(2008) used cards with type written scripts to teach three school-aged children with ASD to increase their use of script phrases and decrease their perseverative speech. Scripts have also been used for young children, but we often use audiotaped scripts that children can access by pushing a button (e.g., Betz et al. 2011; MacDuff et al. 2007; Reagon and Higbee 2009; Wichnick et al. 2010; Wichnick et al. 2010). For example, Betz et al. used audiotaped scripts with colored stickers on the buttons to teach three preschool children to request snack items. However, there is emerging research on the use of pictorial scripts, appropriate for young children. See Ganz and Flores 2010 for a detailed description of how to use visual scripts to support preschoolers with ASD in play.

Using a changing criterion design, Ganz and Flores (2008) evaluated the effectiveness of visual scripts with preschoolers during playgroups. Three preschoolers participated in playgroups with one to two typically developing peers. During play sessions, the preschoolers with ASD were shown cards with the scripts they learned to prompt them to use the scripts. At the end of intervention, the three preschoolers increased their play behaviors and use of play-related language. Similarly, Murdock and Hobbs (2011) implemented the use of scripts with preschoolers in an attempt to increase the use of play-related language. This intervention, called Picture Me Playing, utilized pictures in addition to written scripts. Using within-subject analysis of intervention versus comparison groups, they found that play-related dialogue increased for the children with ASD who participated in the intervention. Further, participants increased in their use of novel utterances and generalized their play-related dialogue to novel toys.

Although there is limited research on visual scripts for young children, research with older children suggest that it has potential for use with young children ASD. Because many young children are not readers, scripts including or consisting entirely of pictures may be most beneficial. Future research should continue to explore the different types of visual scripts that could be utilized to support young children with ASD in their social and communication skill development.

Social Narratives Social narratives briefly describe social situations by highlighting relevant cues and offering examples of appropriate responding using pictures or other visual aids. Individualized for children with ASD, social narratives can specifically help children with ASD learn social skills, engage in appropriate behaviors, use effective communication, or adjust to changes in routines (Collet-Klingenberg and Franzone 2008). Refer to the work of Gray (2000) for examples and instructions for creating social stories.

Since the early 1990s, researchers have been studying the effectiveness of social stories for individuals with ASD. Two recent comprehensive reviews of the social stories literature have concluded that further rigorous research is needed (Karkhaneh et al. 2010; Test et al. 2011). Karkhaneh et al. found that out of six controlled trials which met their predefined criteria for quality research in their systematic review of the literature published between 2002 and 2006, only five showed statistically significant benefits for social interaction outcomes. However, Test et al. conducted a meta-analysis with 18 studies using single-case experimental designs published between 1995 and 2007, and concluded that since only six of those studies indicated "effective" or "very effective" results, there is not enough evidence at this time to support the use of social stories as an evidence-based practice. Thus, while social narratives may be beneficial in modifying target behaviors for some children with ASD, they may be generally ineffective in producing robust behavior changes (Karkhaneh et al.; Test et al.).

Although the existing social stories literature has been limited to mostly school-age children, four studies using single-case experimental design research have been conducted with and show some positive effects for young children with ASD at this time (Crozier and Tincani 2005; Crozier and Tincani 2007; Kuoch and Mirenda 2003; Ozdemir et al. 2008). Using a multiple baseline design across three 5- to 6-year-old children with autism, Ozdemir et al. (2008) implemented multimedia social stories which resulted in increases in the duration of appropriate social engagement in the classroom setting. Additionally, Kuoch and Mirenda also found a reduction of the frequency of target undesired behaviors in three preschoolers with ASD with the use of a social story; however, an ABA design was used which is insufficient for determining a functional relationship. Building upon that research and using more rigorous methodology, in a reversal design, Crozier and Tincani (2005) found that disruptive behavior of a child with autism in the preschool classroom was reduced with the use of a social story and even more so when paired with verbal prompting. Finally, in an inclusive preschool setting, an increase of appropriate behaviors was observed for three young children with autism with the use of social stories implemented using an ABAB/ABACBC design (Crozier and Tincani 2007). Further research using rigorous methodology is required to validate the effectiveness of social stories for young children with ASD (Test et al. 2011; Crozier and Tincani 2007).

Power Cards A Power Card is a visually based support that explicitly teaches an individual with autism how to behave or respond in a specific situation, often social (Gagnon 2001). A Power Card is similar to a Social Story in this explicit instruction; however a Power Card uses a special interest or favorite character as a central component of the story which serves as motivational tool when teaching the desired behavior. Once the social skill deficit or problem behavior is identified, along with the child's hero or special interest, the Power Card scenario and card are then developed in accordance with the child's reading level and comprehension skills. The scenario is written in the first person, relates the child's hero or special interest, and describes solutions to the problem(s) that have presented difficulty for the child. The Power Card summarizes the guidelines set forth in the scenario and includes a picture of the special interest/hero. The Power Card is then reviewed with the student prior to targeted situations (Gagnon 2001).

Five studies have examined the effects of Power Cards on the behavior of individuals with ASD, with one study specifically targeting a child in an early childhood setting. Spencer et al. (2008) used the Power Card strategy to increase time playing on the playground for a 5-year-old boy with autism. After using a Power Card featuring a story about Lightening McQueen, a favorite animated movie character, the research team observed an increase in minutes spent on the playground with peers (Spencer et al. 2008). Several recent studies targeting elementary aged students with ASD have found positive effects for the use of Power Cards on transition latency (Angell et al. 2011) and direction following (Campbell and Tincani 2011). Additional studies include the successful application of Power Cards to adolescents with Asperger's in increasing conversational skills (Davis et al. 2010) and to an elementary aged student in increasing sportsmanship (Keeling et al. 2003). Power Cards appear to have promise for young children with ASD, but additional research is needed with this population.

Visual Cues

Visual cues are reminders of what a child should be doing before, during, or at the conclusion of an activity. These cues can take on a variety of visual forms. Following is a discussion of visual supports for initiating, visual supports for choice making, visual timers and finished boxes.

Conversation and Initiation Cues Children with autism often benefit from supports that signal how or when to start conversations or join play activities. Common cues include pictorial representations of what the child would like to do or say. Much of the research on visual initiation cues is in relation to the Picture Exchange Communication System (PECS) program, which is discussed in a previous chapter. Other research on initiating conversations is related to the use of scripts (Krantz and McClannahan 1993), which is covered previously in this chapter. However, one study has evaluated the use of a non-PECS visual initiation cue in the absence of a script with young children.

Using a multiple probe across participants design, Johnston et al. (2003) found that three preschool children could successfully use a graphic symbol representing "Can I play?" to join play activities with peers. Children were taught to use the graphic symbol in natural play through modeling, prompting, and the delivery of natural consequences. All three children increased their unprompted use of the symbolic communication during the intervention phase. Further, there was some evidence that the children could maintain and generalize this skill. More research on this type of visual support is needed.

Visual Supports for Choice Making Allowing individuals with ASD opportunities to make choices throughout the day has proven an effective instructional strategy in a number of studies (Peterson et al. 2001; Ulke-Kurkcuoglu and Kircaali-Iftar 2010) and choice making is a well-established intervention across disability areas (Dyer et al. 1990; Umbreit and Blair 1996). Though not central to choice making interventions, visual supports can play a role in assisting individuals with autism to better participate in and understand choice making opportunities. Vaughn and Horner (1995) demonstrated this concept in their study of concrete (i.e., photographs) versus verbal choice systems with an adult with autism. When presented with verbal only choices, such as listing 3–5 food choices at mealtimes to select from, researchers and staff were more likely to observe food rejection and aggressive behavior from the individual with autism than when the choices were presented visually as well. It is hypothesized that the concrete choice system assisted with comprehension and word retrieval, as perhaps when the choices were delivered only verbally the individual did not truly understand the information, or perhaps his rote response to the verbal only choices were not reflective of his preferences.

Several examples in the literature are described to illustrate how visual supports can be used in combination with choice making interventions with young children with ASD. These are only a sample of a myriad of possibilities/studies and further discussion of the use of visuals to support choice making can be found in Chap. 23 (PECS). In a recent study with several 5-year-old children with ASD, researchers examined the impact of choice making during discrete trial activities on on-task behavior (Ulke-Kurkcuoglu and Kircaali-Iftar 2010). Children were offered several transparent boxes which held the items used in specific discrete trial tasks and could select the box of their choice. Once the activity was selected, the children could then choose specific materials (i.e., colored pencils or crayons for a fine motor task) to be used in the activity in a similar fashion. The boxes with the items inside severed as a visual support during the choice making opportunity, allowing students to "see" their choices (Ulke-Kurkcuoglu and Kircaali-Iftar 2010). In the choice condition, three of the four students showed improvement in on-task behavior.

Similarly, picture cards were used as a visual support to facilitate choice making with two preschool children with ASD (Harding et al. 2002). In a study examining the effect of choice making on destructive and disruptive behavior, 3-year-old boys were provided word/picture cards to assist in indicating what condition (work or play) they preferred. The choice condition, facilitated by use of the visual support, produced increased compliance with parental demands and reductions in problem behavior. In a similar study with two additional preschool boys with ASD, Harding et al. (2009) produced similar effects with the use of a word/picture card during a work/play choice condition.

Visual Timers A visual timer assists individuals with ASD in predicting when an activity is finished and/or when reinforcement will be delivered. A visual timer serves as a visual warning device to alert an individual of the time remaining during an activity or the time remaining prior to reinforcement (Dettmer et al. 2000). Research indicates that individuals respond well to knowing that reinforcement will be available (Vollmer et al. 1999) and a visual timer is one method of providing that information. Two types of visual timers have been used in ASD research—a digital timer that visually counts down as time passes and a TimeTimer™, a visual timer which displays a section of red indicating an allotted amount of time which then disappears as time passes. Three studies including individuals with ASD and the use of visual timers were reviewed, however, only one included a child of age five or under. Dettmer et al. (2000) includes the use of a TimeTimer™ as part of an intervention package to facilitate transitions with a 5-year-old boy with autism. The timer was set during free time activities to indicate when the upcoming transition would occur. Transition latency decreased when the intervention package was implemented and anecdotal evidence suggested that the participant frequently referenced the visual timer and would prepare to begin his transition when the red portion on the timer was almost gone.

A TimeTimer™ was also used with an 11-year-old girl with pervasive developmental disorder (PDD) in a study conducted by Grey et al. (2009) to increase appropriate waiting behavior. Researchers found that the timer served as discriminative stimulus to indicate when reinforcement would be delivered and was more effective in decreeing tantrums during waiting periods than verbal cues. Similarly, Schadler et al.'s (2009) study with two adults with autism found that a visual cue, the digital timer, was more effective in supporting delayed reinforcement than a verbal reminder (i.e., "You can get another piece of food in 15 s") and contributed to an overall reduction in aggressive behavior with one participant (Schadler et al. 2009). Conceptually, visual timers seem helpful in supporting young children with ASD, however, further research is needed to understand in what conditions visual timers are most useful and in what ways behavior or skill development will be affected.

Finished box A finished box is a visual support that clearly identifies where completed items are placed (Dettmer et al. 2000; Mesibov et al. 2005). A finished box may be a basket, container, folder, or any other visually defined location where individuals are consistently taught to put materials when they are completed or just before a transition is to take place. Developed by Division TEACCH, finished boxes are typically used as a component of a structured work system, described previously. However, one study examined the use of a finished box specifically, rather than as a component of a work system. Part of an intervention package to support transitions, Dettmer et al. used a finished box to assist a 5-year-old boy with autism during transitions to and from work and free play activities. The use of the finished box, along with other visual supports described below, decreased the child's latency during daily transitions. Further efficacy of the finished box strategy for young children with ASD can be found in the work systems studies described previously.

Video-Based Visual Supports

With recent increases in the usability and accessibility of technology, video-based instruction (VBI) has become a popular approach to teaching new skills to individuals with autism. Rayner et al. (2009) defined VBI as any teaching procedure that delivers instruction via video footage; the different types of VBI include video modeling, video self-modeling, video feedback, video prompting, video priming, and computer-based video instruction. Over the past 10 years, numerous research studies have shown that children with ASD can learn a wider variety of skills when VBI is used to deliver instruction.

Although VBI could be listed within several of the broad instructional categories for children with ASD, it is best conceptualized as a visual support for several reasons. First, VBI is hypothesized to be effective for the same reason other visual support strategies are effective; visual–spatial skills are often an area of preference and relative strength for children with ASD (Rayner et al. 2009). Second, similar to other visual supports, VBI allows for visual organization of information and increased saliency of important visual stimuli (Sherer et al. 2001). When video is used as a medium for instruction, children with ASD may be more likely to attend to the relevant stimuli (Sturmey 2003). Additionally, VBI could be included within other subcategories of visual supports within this chapter, as it serves as a tool to both support expectations and provide cues.

Video Modeling Video modeling has the most empirical support of all the VBI procedures and has been used to teach a variety of skills to young children with autism. Video modeling is a procedure whereby an instructor shows a video of a model performing the target skill to a child and then provides the child with an opportunity to perform the same response (Bellini and Akullian 2007). Based on a social learning conceptualization (Bandura 1977), video modeling is presumed to be effective when a child is interested in the model and has the cognitive capacity to store and retrieve the sequence of events that occur in the video. Interest in the physical characteristics of the model is hypothesized to increase the child's likelihood of paying attention and to increase the child's motivation to imitate the model at a later time (Darden-Brunson et al. 2008). Another aspect of video modeling thought to be influential for individuals with autism is a preference for attending to video displays over attending to live models (Charlop-Christy et al. 2000).

Among the benefits of video modeling when teaching children with autism are that the video can be presented immediately prior to naturally occurring opportunities to perform the target response, the same video clip can often be used with multiple students, and video editing allows for increased saliency of environmental stimuli that correlate with the target behavior (i.e., relevant antecedents and consequences). The increased saliency may increase motivation and facilitate faster acquisition. Collectively, these features make video modeling an efficient approach to instruction that educational service providers may find especially beneficial for students.

The first application of video modeling to individuals with autism involved a comparison of behavior skills training versus video modeling to teach grocery-shopping skills to adolescents and adults (Haring et al. 1987). Haring et al. found that behavioral skills training in a single store led to skill acquisition without generalized responding whereas video modeling led to generalized skill acquisition across environments and without prompts for all participants. Video modeling proved to be a more efficient intervention than training in a single environment. Charlop and Milstein (1989) extended video modeling to younger children with autism and found that boys with mild autistic impairments increased and maintained their conversational statements following exposure to video modeling. Importantly, response prompts (i.e., written scripts or verbal reminders) were not necessary and both participants demonstrated generalized responding across settings, conversational partners, and stimuli. Though it has not been experimentally evaluated, the omission of response prompts may be one of the attributes of video modeling that contributes to generalization and maintenance of trained behaviors. Numerous replications of video modeling interventions have demonstrated the generality of the procedure for teaching a variety of skills to children with mild or moderate autism (Charlop-Christy et al. 2000; Gena et al. 2005; Hine and Wolery 2006; Paterson and Arco 2007; Reagon et al. 2006; Sherer et al. 2001).

Plavnick and Ferreri (2011) recently evaluated the effectiveness of video modeling to teach preschool children with autism to request preferred items or activities. All participants had a vocabulary of less than five words prior to intervention though three of the four acquired three or more vocal requests after video modeling was introduced. A fourth participant viewed videos of peers exchanging picture cards to communicate requests and then acquired the exchange response without prompts other than the video. Target requests were maintained after the intervention was terminated and were generalized to a range of instructional settings.

Though the precise prerequisites and learner specific attributes that influence the effectiveness of video modeling for an individual child are not yet known, the intervention is effective more often than not (Bellini and Akullian 2007). Video modeling has been used to teach numerous behaviors to preschool aged children with autism and has therefore been classified as an evidence-based practice by several different reviews (Bellini and Akullian; NPDC; Reichow and Volkmar 2010).

Video Self-modeling One of the original tenets of social learning theory was that individuals are more likely to attend to and imitate models with whom they share physical characteristics (Bandura 1977). This assumption has led to a line of research to determine whether the individual herself is an effective video model (Buggey 2005). Though the necessity of similarity to the model has yet to be empirically validated in video modeling literature for children with autism (Rayner et al. 2009), the assumption of video self-modeling is that the participant is likely to identify with a model who shares 100% of the observers characteristics. Some potential benefits of video self-modeling are that children may be more motivated to attend to video of themselves and may therefore be more likely to increase certain behaviors as a result of watching their own positive performances.

The most common use of video self-modeling is when a child can already perform a behavior but does not emit the behavior often enough or under an appropriate range of environmental conditions (Rayner et al. 2009). For example, a child may respond to social bids initiated by adults but not those made by same-aged peers. Similarly, a child might play with only a limited number of toys. Video self-modeling can be used to increase the range of people or toys that a child interacts with appropriately.

Wert and Neisworth (2003) used video self-modeling to teach children with autism who emitted a few spontaneous requests (i.e., mands) to increase requests during the school day. Participants viewed videos of themselves requesting preferred items prior to going to school. All participants demonstrated an increase in requests following the video self-modeling intervention and maintained these requests at a higher level than baseline up to 6 weeks following the termination of the intervention. Buggey (2005) demonstrated that video self-modeling can be an effective way to address a range of behaviors including increases in language and social initiations and decreases in tantrums and aggression. Video clips of each of five participants performing the desired behaviors were prepared and edited to remove all negative exemplars and adult prompts. Immediately after viewing "self-as-model" videos, participants demonstrated positive changes in behavior that were maintained after the intervention was stopped.

Despite positive outcomes, there are some potential challenges to implementing video self-modeling that need to be considered prior to selecting this approach over traditional video modeling. First, video self-modeling often requires extensive video recording and/or editing, as the modeled sequences cannot be scripted as they are with typically developing peers as models. Instead, video needs to be constantly collected in order to capture naturally occurring instances of the individual performing the behavior or an adult needs to prompt the response and prompts need to be carefully edited out of the final video exemplar. These steps increase the effort needed to create the video clips and may be a barrier to widespread use. An additional limitation of video self-modeling is that a video collected for one student is less likely to be an effective video model for another student with autism, thus, reducing the overall efficiency of the intervention.

Though direct comparisons of video modeling and video self-modeling do not suggest one is clearly more beneficial than the other, some children demonstrate better learning outcomes when video self-modeling is used (Marcus and Wilder 2009). Unfortunately, there is no clear research demonstrating why video self-modeling might sometimes be more effective or for which children it is most beneficial. Nevertheless, video self-modeling can be used to teach language, social, play, and functional skills to children with autism and it may offer some benefits that are not apparent when peers are used as models.

Video Feedback, Prompting, and Priming Researchers have started looking at adapting other types of instructional procedures commonly used for children with autism to include video-based components. This includes video feedback, video prompting, and video priming (Rayner et al. 2009). Though these methods share similarities to video modeling, they are identified as distinctly different interventions based on the information presented within the video and the timing of the video display (Schreibman et al. 2000).

A similar strategy to video self-modeling is video feedback. When using video feedback, an instructor records multiple videos of the target child engaging in a particular behavior and shows both the positive and negative examples of the performance to the child (Rayner et al. 2009). This provides the child opportunities to evaluate her performance across a series of instructional conditions and has been effective in decreasing a number of problem behaviors or increasing levels of previously acquired desirable behavior emitted by children with autism. Video feedback is similar to video self-modeling in that the child watches himself performing target skills. In fact, when the child views positive performance exemplars, video feedback looks identical to video self-modeling. However, negative exemplars are not used in video self-modeling as they are in video feedback.

Video prompting is similar to video modeling though it is typically used to teach behavioral chains as opposed to an isolated behavior (Canella-Malone et al. 2007). Canella-Malone and colleagues used video priming to teach components of a complex skill to individuals with autism by showing a single component within the chain and immediately providing an opportunity for the child to perform the same component. Each step within the chain was taught in this manner and the participants could then perform the entire behavioral chain. As in the previously discussed

VBI approaches, the model can be a peer, an adult, or the child herself.

Video priming involves showing a video that is captured from the perspective of the person performing the behavior (also referred to as point of view video modeling) and may include only a portion of the task. This type of approach has been used to promote appropriate transition from one setting to the next (Schreibman at al. 2000), social orienting and eye contact (Tetreault and Lerman 2010), and toy play (Hine and Wolery 2006). Distinct from video modeling, video priming may limit the length of the video to show the learner a few steps necessary to begin the task and then allow the child to perform the entire task himself. The second feature of video priming that differentiates it from video modeling is that video displays only the environment or relevant tangible stimuli but does not include other people performing a specific target behavior. It is hypothesized that video priming increases the predictability of particular events, which sets up appropriate responding when the real situation occurs (Schreibman et al. 2000).

Computer-based Video Instruction An emerging method of VBI is to use a computer to deliver instruction and include video as one component within the overall procedure. This VBI method combines video technologies and computer assisted or delivered instruction to teach new skills (Mechling 2005). Unlike procedures used with most other VBI strategies, the learner is not dependent on another person to facilitate the use of or presentation of the video display; instead, the child controls the multimedia. This allows for increased independence and gives the child opportunities to review components of the procedure multiple times whenever desired.

The majority of studies examining computer-based video instruction have involved older students with autism, though a few investigations suggest this may be beneficial for younger individuals on the autism spectrum (Hagiwara and Myles 1999). Hagiwara and Myles examined the effects of embedding social stories within a computer program to teach hand-washing skills to elementary aged students with autism. The results showed a slight increase in hand washing for all participants as the multimedia intervention was introduced. Computer-based video instruction has the least empirical support of all the VBI procedures for young children with autism. The benefits of the methodology for older individuals along with a recent increase in technology within early intervention classrooms suggests more research is needed in this area. If young children with autism are able to independently learn from a computer or other technological device, it may be a sustainable approach to lifelong learning for these individuals.

Conclusions and Future Directions

Visual supports are clearly a widely used and well-researched focused intervention practice for individuals on the autism spectrum. With the recent emphasis on and greater understanding of the processing strengths and needs of individuals on the spectrum, particularly young children, and armed with first-hand accounts from individuals on the spectrum citing the importance of visual supports, researchers and practitioners are likely to continue implementing and studying the effects of such supports. There are a number of visual supports that have a range of evidence of effectiveness for individuals with ASD. Fewer of those, however, have evidence directly linking the use of visual supports to behavior change for very young children on the spectrum. Following are a number of areas for future discussion and study in the area of visual supports and young children with ASD:

Use of Technology

As technology continues to become more accessible to educators, it is likely that the future directions for visual supports will involve this technology. Tablets and smartphones already enable portable visual supports such as timers, schedules, and video models that allow an educator to carry a range of visual supports in his/her pocket and use them as needed. This is much less cumbersome than systems that rely upon hundreds of picture symbols or tangible materials needed for each system. In fact, a recent publication titled *Apps for Autism* (Brady 2011) identifies over 200 technology-based applications for download that directly relate to the needs of individuals with ASD. An additional benefit of visual supports being housed in one powerful technological device is that children may be able to manage their own visual supports once they learn to use the device. Previous systems that required training on how to use each support may not provide the same benefit.

There are concerns, however, about the use of these technology-based tools with young children, specifically around how a toddler or preschool aged child could safely and appropriately manage such a device, the costs associated with using such a device, and the increased screen time for young children, as the American Association of Pediatrics discourages parents from allowing screen time for infants and children under 2 years of age (AAP 2011). As the field continues to evolve, researchers, families, and practitioners will need to collaborate to navigate through and respond to these concerns.

Application to Young Children

Extending the use of a number of visual supports to the toddler and preschool age population is a logical future direction. However, when extending these supports to very young children, additional considerations are required. First, the format and length of the visual support must be carefully selected to match the developmental level and functioning of the young child. Next, current literature in visual supports glaringly lacks application in the home setting. While school and community contexts are valuable, the use of visual supports in the home is likely most appropriate for very young children. Efficacy of some visual supports may vary across context and requires further study. In addition, few visual supports reviewed were implemented by family members. Again, if visual supports are to be effective with toddlers, the study of caregiver-mediated intervention is also needed. A better understanding of the training required for family implementation and the fidelity in which family members can implement supports is also necessary. Last, family perception of intervention acceptability and feasibility is needed, similar to the reports of acceptability found in school-based studies (e.g., Carnahan et al. 2009).

Intervention Components and Implementation

As illustrated in this chapter, there is a great deal of overlap in terminology and strategies among and between specific visual supports, specifically around visual schedules, activity schedules, work systems, and their related components. In addition, social narratives, scripts, and Power Cards share a number of common features. This is one reason why researchers have a great responsibility in clearly defining the components of their visual support interventions and carefully tracking the implementation of each component. This will assist in accurately identifying what intervention is being used and what features of the intervention contribute to its success, which increase the likelihood that practitioners and family members can successfully implement the intervention. Component analyses may also allow researchers to better understand what intervention features are likely to be most beneficial for specific children on the spectrum. The limited use of implementation measures is well documented in the autism field (Wheeler et al. 2006), yet is extremely important as this line of research continues to evolve.

Building on the already strong empirical evidence for visual supports, and the careful consideration of the above issues, the application of these supports to young children with ASD is likely to lead to meaningful behavior change.

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Teaching Verbal Behavior to Children with Autism Spectrum Disorders

16

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Keywords

Verbal operants · Language · Verbal behavior

It has often been said that the characteristic which distinguishes humans from all other animals is the capacity for language (Pinker 1994). It is essential to our species and contributes to its survival in various ways. An understanding of spoken and written rules, for example, represents an efficient means of learning, whereby certain undesirable consequences can be avoided altogether (e.g., one does not need to be hit by a car when crossing the street to know to first look before crossing). It is also the medium by which our culture is propagated. Folklore, traditions, values, societal norms, and laws are all passed down from one generation to the next through language. Thus, it is an imperative of our species not only to understand others, but also to develop an effective means of communication by which one can be understood.

But what does it mean to "understand" something? Prior to discussing this question, it is critical to first have an idea of what the terms "language" and "communication" signify. Simply stated, language may be defined either as the acquisition and use of complex systems of communication (Dell Publishing 1994), or to a specific example of one of these systems, such as English, French, or Portuguese. Communication consists of an exchange of ideas or information, which may be transmitted through various means (e.g., written, spoken, signed, etc.). Communication, to fit its definition, necessarily requires the sharing of something (the Latin word "communis," means "to share"), between a sender and a recipient, and an instance of communication can be considered complete once the recipient has demonstrated some understanding of the message transmitted. By extension then, understanding may be defined as a bidirectional relationship between a sender's message (i.e., the person speaking) and the recipient's (i.e., the listener) action or reaction to this message. If the listener responds in accordance with the message and the speaker's desired outcome is achieved, one can infer that he/she has understood the underlying meaning of the message. This underscores the importance of fluency and context, as both parties must be familiar with the same language to effectively communicate with one another. Whilst these terms are very generally defined here, there exist some important distinctions between schools of thought concerned with human

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language development. The question of how humans acquire language is one that continues to be hotly debated amongst intellectuals concerned with the topic.

From a traditional (i.e., linguistic) perspective, language is regarded as an innate capability unique to humans (Chomsky 2006; Jackendoff 1995; Pinker 1994). It is said to be "hard wired" in the brain, residing in specific areas of the cortex (i.e., Broca's and Wernicke's areas), whose complexities are yet to be unraveled and understood completely. Those ascribing to this perspective view language as an immoveable entity—one is either born with the prerequisite biology to produce language, or not. According to Pinker (1994):

> Language is not a cultural artifact that we learn the way we learn to tell time or how the federal government works. Instead, it is a distinct piece of the biological makeup of our brains. Language is a complex, specialized skill, which develops in the child spontaneously, without conscious effort or formal instruction, is deployed without awareness of its underlying logic, is qualitatively the same in every individual, and is distinct from more general abilities to process information or behavior intelligently. (pp. 4–5)

By this logic then, what makes humans *human* is the inherent make up of our brains. According to this paradigm, a human child is born with the necessary structure required to both produce and understand language. The evidence cited in supporting this assumption lies in the fact that human language acquisition is a process that is observed universally and without the need for specific teaching or training (Pinker 1994).

From a behavioral perspective, the one we subscribe to, language is analogous to any other behavior (Skinner 1938, 1953, 1957, 1969). It is learned as opposed to innate, shaped from its simplest to most complex form over time, and therefore malleable. Though the underlying biology of the organism is an important variable in that it may impose limits on the realizable potential (Michael 1993), context and function are assigned primordial importance in language development. This is an optimistic perspective, because it suggests that language is learned, and thus it can be taught to those who lack it.

In the sections below, we will discuss language development from this perspective, with a specific focus on the impairment of communicative repertoires as it relates to individuals diagnosed with autism spectrum disorders (ASDs), and present empirically supported methods for remediating language delays.

Diagnosis

Over the course of the past 10–15 years, autism has increasingly become a hot-button topic. The most current statistics reported by the Centers for Disease Control and Prevention (CDC)[1] estimate that this type of developmental disorder affects approximately 1 in 88 children, with these numbers steadily increasing over the past decade. The word "autism" is an umbrella term, and individual diagnoses fall along a spectrum. For each child affected, this may mean the diagnosis provided is different (i.e., autistic disorder, pervasive developmental disorder—not otherwise specified, Asperger's syndrome, etc.). While each child manifests symptoms in a unique manner, diagnoses are made based on the demonstration of certain core symptoms, all of which remain the same across individual diagnoses. Briefly, these include significant impairments in the following domains: social interaction, communication, and stereotyped and repetitive patterns of behavior (4th ed., text rev.; *Diagnostic and statistical manual of mental disorders*; American Psychiatric Association 2000).

For the purposes of our discussion, we will focus on one of these primary areas of concern, namely that of language and communication, as this is one of the fundamental abilities upon which all other skills are developed. Children diagnosed with ASDs either demonstrate atypical language development (i.e., delayed or stunted acquisition of comprehension and spoken language), or show a regression in language skills prior to diagnosis. Often, these delays manifest themselves early on in the child's life. A young infant, for example,

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[1] Retrieved from: http://www.cdc.gov/ncbddd/autism/data.html.

may not begin to babble or imitate sounds at the expected and appropriate age. On the other hand, he/she may begin to babble, imitate, and develop a preliminary vocabulary consisting of common words according to the expected developmental milestones, but may then "lose" this ability in a trend counter to that of typically developing peers. In other cases, the young child may begin to babble and imitate, and remain seemingly halted at this phase of language development, often repeatedly making the same sounds regardless of context. Deficits in this domain of development inevitably lead to a host of other behavioral problems (e.g., protracted tantrums, aggression, and other maladaptive forms of behavior). Without an effective and appropriate means of communication, other forms of behavior fill the vacuum, which eventually result in the social stigmatization and ostracism of the child. While closely associated with some of the other core diagnostic criteria, the wide variety of behavior excesses and deficits demonstrated by children with autism often have at their core a deficit in language and communication (Durand and Merges 2001). Additionally, the development of an effective language repertoire is considered to be one of the best predictors of outcome (amongst others) for children diagnosed with an ASD (Szatmari et al. 2003). Once this underlying deficit is addressed, it is often observed that other related behavioral problems are rectified.

Treatment

Thus far, the only scientifically supported treatment for autism consists of intervention (s) based on the principles of behavioral science (i.e., applied behavior analysis [ABA]), and the degree to which intervention adheres to its scientific underpinnings seems to be directly correlated with outcome. In a seminal study published by Lovaas (1987), the author evaluated the effectiveness of behavioral intervention on the developmental trajectory of children diagnosed with ASDs. Broadly speaking, changes in IQ (as measured by a battery of standardized assessment measures), academic performance, and subsequent classroom placement were utilized to help assess the effects of intensive (i.e., 40 h per week) behavioral intervention, delivered to a treatment group over a period of 2 or more years. Measures obtained for this group were compared against a control group. The results indicated that over 47 % (N=19) of those children assigned to the treatment group achieved normal intellectual functioning and were successfully placed in typical classrooms without additional support following the conclusion of the study. Of the remaining children in this same group, another 40 % were reclassified as mildly retarded following intervention and placed in classrooms specializing in educating children with language delays, while only 10 % remained in the profoundly retarded range and required significant assistance in their classroom placements. In comparison, only 2 % of the children in the control group achieved the same outcomes as those placed in regular education classrooms from the treatment group, while 45 % were reassessed with mild retardation and placed in classrooms addressing language delays and 53 % were classified as profoundly retarded and required the types of supports provided in specialized autism classrooms. The study conducted by Lovaas was the first of its kind and demonstrated the impact of intensive behavioral treatment on the IQ, intellectual functioning, and subsequent independence of children diagnosed with ASD's.

Since the article appeared in print, several more of its kind have been published in various journals demonstrating similar outcomes (Bibby et al. 2001; Eikeseth et al. 2002; Eikeseth et al. 2007; Eikeseth et al. 2012; Hayward et al. 2009; Howard et al. 2005; McEachin et al. 1993). For example, McEachin et al. (1993) found that preschool-aged children diagnosed with autism (N = 19) receiving intensive behavioral intervention, achieved less restrictive school placements and higher IQs overall than children included in a control group (N = 19). Additionally, more extensive evaluations were conducted with the nine participants in the experimental group achieving the best *outcomes,* and data obtained from intelligence tests and measures of adaptive behavior showed they were indistinguishable from same-aged typically developing peers. Furthermore, follow-up measures (collected at a mean age of 13 years for children included in the experimental group, and 10 years for those included in the control group) showed that gains made were maintained as children grew older, suggesting that intervention based on behavioral science may produce both significant and durable gains for children diagnosed with autism.

In 2005, Howard et al. published a study demonstrating the effectiveness of intensive behavioral intervention in comparison to more traditional approaches. The treatment group ($N=29$) received intensive behavioral intervention only (i.e., no other treatments were implemented) for 25–40 h per week, while a comparison group ($N=16$) received "eclectic" intervention consisting of a combination of 1:1 and 1:2 intervention in a public special education setting. A second comparison group ($N=16$) received non-intensive intervention consisting of a combination of methods and small group teaching for up to 15 h per week in a public early intervention program. Standardized tests were administered at the onset of intervention for all participants, and again approximately 14 months following the onset of treatment and measured key indicators of cognitive, adaptive, and language skills. While all participants initially scored very similarly on these measures upon intake, only children who had received intensive behavioral intervention showed a statistically significant increase in standard scores across all domains measured, including, and especially in the language domain.

Similarly, Hayward et al. (2009) examined the progress of children with autism following 1 year of intensive behavioral treatment (i.e., children received a mean of 36 h per week of one-to-one treatment) and compared a clinic-based model ($N=23$) to a parent-managed model that included intensive supervision ($N=21$). Results obtained showed that all children, across both groups demonstrated significant improvement across the following measures: IQ, social skills, motor skills, adaptive behavior, and perhaps most notably, language (production and comprehension) skills.

Finally, in the most recent article published on the same topic, Eikeseth et al. (2012) examined the effects of early and intensive behavioral intervention (EIBI) delivered in community settings on the adaptive behavior of children diagnosed with autism. Across all participants ($N=35$), children receiving EIBI scored significantly higher than children in a "treatment as usual" ($N=24$) group following 1 year of intervention. More specifically, while all participants scored similarly at intake, children in the EIBI group obtained significantly higher scores on all scales of adaptive behavior, showed reductions in maladaptive behaviors, and reductions in the aforementioned symptoms characteristic of autism.

As stated above, one of the defining symptoms upon which a diagnosis of autism is made consists of impairment in language development. In all of the studies conducted thus far examining the effects of intensive behavioral intervention in children diagnosed with autism, results show a marked improvement across all developmental domains. Most noteworthy, perhaps, is the improvement in language. Across outcomes studies measuring the effects of ABA on language development, children made significant gains in both comprehension and production, often catching up to their same-aged, typically developing peers.

It would be negligent to ignore the efficacy of other interventions such as those implemented by speech and language pathologists. However, it should be noted that in most, if not all cases, the characteristics that make an intervention effective rely, whether explicitly designed to do so or not, upon the principles of behavioral science. For example, rewards may be used to motivate a child to work with a diagnostic professional and delivered following completion of certain tasks, exemplifying the principle of reinforcement (Catania 2007). Similarly, initial assistance may be provided by a speech and language pathologist in the form of physical assistance when teaching a child the correct mouth placement to form a particular sound or word, and gradually removed as the child demonstrates increasingly greater amounts of independence, exemplifying the use of prompting, shaping, and fading procedures (Miltenberger 2008). Thus, despite the plethora of interventions which currently exist for teaching communication to children with autism, it can be argued that the effective ones utilize principles of behavior analysis, albeit perhaps inadvertently so, and can therefore also be considered behavioral.

Verbal Behavior

As previously mentioned, a behavioral approach considers language to be a behavior like any other (Skinner 1957). Generally speaking, behavior is considered to be something any living organism does. This includes both unlearned and learned behaviors. This perspective also considers behavior that is performed both overtly, or at the public level where it is accessible and observable by others, as well as covertly, or at the private level where it may not necessarily be observable (e.g., thoughts, feelings, and states; Skinner 1974). Language is no exception, and falls within both the public and private realms. At the overt level, it can be specifically and precisely observed, measured, and quantified and therefore shaped and changed. It is susceptible to the same environmental consequences (e.g., reinforcement, punishment, response effort, etc.) that affect the occurrence and dimensions (i.e., frequency, intensity, time lapsed prior to responding, etc.) of any other behavior.

It is important to note here that from this perspective, all behaviors also serve a specific function (Iwata et al. 1994). That is, living organisms engage in certain behaviors not only because of a history of experience with certain environmental influences, but also to produce certain consequences based on a previous history of learning, whether consciously or not. Additionally, the form of behavior, however convoluted it may seem, becomes a less relevant feature than its function. This is also true of language (Kelley et al. 2007; LaFrance et al. 2009; Lerman et al. 2005; Normand et al. 2008). This becomes a critical consideration in selecting the replacement of maladaptive forms of behavior with more functional, acceptable, and adaptive ones. In the majority of cases, behavior excesses demonstrated by children diagnosed with ASDs serve a function that can be effectively replaced with communication (Carr and Durand 1985; Durand and Carr 1991; Durand 1999; Kahng et al. 2000; Wacker et al. 1990). For example, if a child engages in biting to get out of doing something, teaching the child to request a break or to terminate the task not only serves the same function (i.e., this new behavior is functionally equivalent to the old one) but is much more acceptable and likely to result in continued contact with reinforcement in the natural environment, helping to guarantee its robustness and duration over time (Durand and Carr 1992).

Thus, if problem behaviors have communicative function, it seems obvious that any intervention should incorporate, if not have a targeted focus on teaching functional language from its onset. Furthermore, as mentioned above, without an appropriate means of communication, children may not only continue to develop problem behavior, but will also miss out on many critical opportunities to learn from their surrounding community.

Verbal Units (Operants)

As our focus is primarily on functionality, we will use the terms language and communication as synonyms. In actuality, we prefer the term verbal behavior (Skinner 1957), as it shifts attention to the variable clinicians can manipulate: the environment. The term *verbal behavior* was first coined by Skinner (1957) in his seminal book by the same name. In it, he conceptualized language for the very first time from a behavioral perspective, taking into consideration both context and the importance of functional consequences. Skinner's account provided a potentially pragmatic way of teaching language and addressing impairments. It gave scientists and practitioners alike a taxonomy by which to classify language units as well as a systematic approach to measuring and, most importantly, changing language.

In his analysis, Skinner (1957) defines verbal behavior and distinguishes it from nonverbal behavior. Specifically, verbal behavior is defined as the behavior of an individual, which is reinforced through the mediation of another person's behavior (p. 2). Otherwise stated, reinforcement can only be obtained through the actions of another individual. Skinner further refines this definition by stipulating that the behavior of the person mediating a speaker's response (i.e., the listener) must have been specifically trained to serve that function. For example, if a thirsty child (i.e., speaker) says "water" in the presence of an adult, the adult (i.e., listener) will likely reinforce that child's response by providing the requested item: water. The listener reacts in this manner *precisely because* he/she has already learned to get a glass of water when someone asks for one. It is through such means that the verbal community comes to establish control over, and influences its members' (verbal) behaviors.

In sharp contrast, nonverbal behavior achieves its effect on the environment directly. It does not require the mediation of another person (Skinner 1957). Utilizing the same example, a thirsty child could obtain water independently through several means (i.e., getting water out of the refrigerator, pouring himself/herself a cup of water, drinking water from a fountain or faucet, etc.), none of which would necessarily require the presence of another individual.

Furthermore, Skinner (1957) makes the distinction between verbal and vocal behavior. In other words, verbal behavior may be vocal, in the sense that it engages the vocal chords, but this is not a requisite condition for behavior to be considered verbal. To illustrate this point, consider a child with little to no spoken "language," who points to a desired item that is out of reach. If that child is in the presence of another individual (i.e., a listener), he/she will likely obtain that item the same way he/she would have had that child used spoken words. Thus, for the remainder of this chapter, the term verbal will not be used as a synonym of vocal, but to define behavior that produces mediated consequences. In other words, verbal means communicative.

Verbal behavior can be broken down into teachable units according to the specific relations between controlling variables and response forms. These relations are called verbal operants, precisely because of the way they "operate" on the environment. The elementary verbal operants consist of the mand, the tact, the echoic, the intraverbal, textual behavior (i.e., reading), and transcription (i.e., dictation and copying text). Skinner also discusses the role of the audience in the control of large portions of our verbal behavior. Of these relations, there are four which are especially relevant to the initial development of an adequate vocal-verbal repertoire. These are the mand, tact, intraverbal, and echoic, and are defined below.

The mand, according to Skinner (1957), is a type of verbal operant in which the response is reinforced by a characteristic consequence. Using more colloquial terms, this relation may be described as "requesting." Unlike all other verbal operants, however, the mand occurs under the control of relevant conditions of deprivation or aversive stimulation (i.e., motivating operations). These conditions greatly affect the likelihood of the occurrence of the mand. More specifically, a motivating operation (MO; Michael 1982) constitutes any event in the environment, which alters both the reinforcing effectiveness (i.e., the relative value) of a given stimulus, and the relative frequency of a behavior, which in the past has been reinforced with that particular stimulus. Sticking to the example used above, a child who has not had water for some time would respond in ways that in the past has resulted in water. If in the presence of a listener, the child may request (mand for) water, and the reinforcement for the response would consist of receiving the requested item. Thus, it is said that the mand specifies its own reinforcer (Skinner 1957).

The tact, on the other hand, is a verbal operant under the control of a prior object, action, or property (i.e., nonverbal stimulus), and whose response is, at least when learning this behavior, reinforced by some generalized form of reinforcement (i.e., praise). For example, when learning to label objects in his/her environment, a child might see a glass of water (nonverbal stimulus), and say "water," which may result in some form of approval.

The intraverbal is a type of verbal operant under the control of a prior verbal stimulus, and whose response form does not resemble the preceding stimulus. As with the tact, the intraverbal response is initially reinforced by some generalized form of reinforcement. An adult may ask a child, for example, what his/her favorite animal is, and the child may respond by naming any animal within his/her repertoire. The adult's original question evoked the child's response, but neither vocal utterance (adult or child's) resembled the other.

Finally, the echoic consists of a verbal operant under the control of a prior verbal stimulus, with which the response is identical. As with the tact and the intraverbal, the echoic response is reinforced by some form of generalized reinforcement. An individual may say "Hi" to another individual passing by, to which that passerby may respond "Hi." These verbal stimuli are identical in form, and maintained by some type of socially mediated reinforcement such as the other's response, or a smile.

It is of primary importance to note that the acquisition of any one type of verbal operant (e.g., tact) does not necessarily lead to the acquisition of the other verbal operants (e.g., mand). In other words, learning to say "cookie," as when a child sees a cookie, does not necessarily mean that the child will be able to ask for a "cookie" when he/she wants one. This phenomenon is known as functional independence and has been empirically demonstrated by numerous researchers (Hall and Sundberg 1987; Lamarre and Holland 1985; Partington et al. 1994). Thus, although transfer between operants may occur readily in verbally sophisticated and typically developing learners, or under certain teaching arrangements (Finn et al. 2012; Petursdottir et al. 2005), specific training may be necessary to establish each type of verbal operant in individuals with disabilities. This is a critical factor related to the notion of understanding, as we will discuss below.

Language interventions developed according to Skinner's (1957) taxonomy (Bondy et al. 2004; Greer and Ross 2008; Sundberg and Partington 1998; Williams and Greer 1993) have been shown to be highly effective at teaching the verbal operants described above. This model focuses on the function rather than the form of spoken language, and emphasizes the importance of context (i.e., verbal operants). The verbal operants defined above must each be learned as language develops in order to acquire an adequate basic vocal-verbal repertoire.

Since its original publication, Skinner's work has had a significant impact on the way(s) in which language skills are taught. By placing an emphasis on context and function, his taxonomy has given behavior analysis a powerful tool by which to teach and shape language, especially in instances where the communicative repertoire is significantly impacted.

Developing Basic Communication Skills

Assessment

When developing a plan for teaching basic communication skills for a child with autism, one needs to first assess the learner's current repertoire. The results obtained allow for the development of a comprehensive and parsimonious intervention program, by providing important information pertaining to areas of strength and deficit. Unfortunately, despite the abundant availability of language assessments, very few break language down into teachable units such as the verbal operants. This lack of specificity renders most standardized assessments impractical in helping to identify what needs to be specifically taught to the child (Carr and Miguel 2013; Esch et al. 2010). Furthermore, standardized assessments are limited in their time-sensitive nature (i.e., most are valid only when administered according to their intended timelines, such as every 6 or 12 months), making them inadequate in evaluating a child's progress over time, especially when more repeated and frequent measurement is required, as is often the case with intervention programs designed for children with ASDs.

There are at least two assessments developed from a behavioral perspective which have proven to be useful curriculum guides, as they can be used not only to assess the child's initial repertoire, but also his/her progress over time. These assessments are: (1) The Assessment of

Basic Language and Learning Skills—Revised (ABLLS-R; Partington 2006) and (2) The Verbal Behavior Milestones Assessment and Placement Program (VB-MAPP; Sundberg 2008). Both are criterion-referenced assessments that evaluate a child's learning, verbal behavior, and academic repertoires in several domains such as mands, tacts, echoics, intraverbals, play skills, etc. Each yields scores based on direct observation, probing, and data collection. Evaluation, sometimes subjective in nature, as well as the number of skills requiring observation and probing can result in a time consuming process. It should be noted that no data on these assessments' psychometric properties have been published (Carr and Miguel 2013), and research related to these properties is needed. However, given the lack of standardized verbal behavior assessments, and the inadequacy of traditional assessments, behavioral practitioners seem to be making great use of both the ABLLS-R and the VB-MAPP as a way of identifying targets for language intervention.

Once specific targets for intervention are identified, behavior analysts develop lessons using well-researched teaching methodologies derived from behavior analysis (Cooper et al. 2007). Because language is viewed as behavior and behavior is a function of environmental variables, the goal is to create the necessary conditions for the child to learn how to communicate effectively. Some of these environmental arrangements include the use of reinforcing consequences to increase behavior and the manipulation of antecedent variables to make it more likely that the desired behavior will occur.

However, the results of any particular assessment tool often yield a greater number of skills requiring intervention and teaching than can be feasibly targeted within a given period of time (e.g., on a quarterly basis, in a 6-month period of time, from one yearly individualized education plan (IEP) meeting to the next, within the context of service provision over a period of 2–3 years). Additionally, the sheer amount of delay with respect to skills domains, and related to language particularly, often compounds this problem. Therefore, clinicians must carefully prioritize which behaviors will be addressed first, both within and across domains, while simultaneously planning out a more long-term strategy to address whichever skills and behaviors will be remaining to teach. Further, the way in which skills are taught can greatly influence the future need for teaching. For example, intentionally exposing the learner to several different examples of a particular item to be taught (e.g., a blue cup, a red cup, a small cup, a large cup, a cup made of glass, a cup made of plastic) will lead to better generalization and concept formation, than if this strategy were not employed, thereby circumventing a potential future loss of time which would otherwise have to be spent teaching the generalization of skills specifically (Greer and Ross 2008; Stokes and Osnes 1989). This aspect of target selection and prioritization poses a special problem and is a critical component of a comprehensive intervention program, as it ensures that the time spent in intervention is utilized in the most effective and efficient manner possible, by maximizing the amount of learning taking place. This particular issue is addressed by ensuring that the teaching strategies and methodologies incorporated into intervention are empirically supported and well vetted. The problem that remains, however, pertains to which skills to begin teaching. To this end, the concept of behavioral cusps (Rosales-Ruiz and Baer 1997) becomes especially helpful and relevant.

Though similar to the notion of developmental milestones, behaviorally speaking, the concept of cusps is quite different. Cusps are defined as behavior changes that systematically lead to either widespread further changes or to important further changes (Bosch and Fuqua 2001; Rosales-Ruiz and Baer 1997). Importance, in this sense, refers to a change which is valued by either the individual acquiring the cusp himself/herself, significant others in the individual's environment (e.g., the child's family members or teachers), the relevance of the behavior change in response to the environment (e.g., asking for a favorite toy is much more likely to be reinforced and maintained and is much more desirable in general in the social community than tantruming), or a combination of all or any of these. Unlike the notion of stages of development or milestones, the concept of cusps frees the clinician from a perspective that necessarily follows a set and predetermined sequence. Additionally, a very small change may constitute a cusp for the organism, depending upon whether that change will lead to additional change(s).

The focus of a behavioral account of development therefore consists of the individual organism's experience with naturally occurring contingencies in his/her environment. In other words, when the acquisition of a particular behavior brings the organism into contact with different contingencies that will be critical to the subsequent development of more complex or sophisticated behaviors, this is considered a cusp. Additionally, the concept of cusps relies on the relevance and application of contingencies throughout the individual's lifespan. Therefore, what makes a behavior change a cusp is that it exposes the individual to new contingencies, including and especially as this pertains to accessing new reinforcers and/or punishers, new environments (such as enrollment in a preschool), new sources of stimulus control (such as the generalization of skills to the teacher), and new communities that will either contribute toward the maintenance (such as peer groups or the classroom environment), or elimination of certain contingencies (such as rehabilitation centers for individuals engaging in substance abuse). Cusps, as a result, are often identified by their effects, in that they lead to generative and/or novel behavior and facilitate future learning by functioning as "either a prerequisite or a component of more complex responses" (Bosch and Fuqua 2001, p. 124). The use of the term refers to the *potential* for the expansion, refinement, and recombination of other, less developed repertoires into more sophisticated ones. The net result necessarily leads to both more as well as accelerated learning and competing with the emission of inappropriate responses.

Some general examples of cusps almost every human being will contact throughout the course of his/her lifetime include learning to sit upright, learning to crawl and then to walk, learning through observation of others, and learning to read. Additional examples may include experiences of a more undesirable nature, such as being exposed to addictive substances for the first time. Although this may seem counterintuitive, such experiences inevitably expose the individual to new forms of reinforcement and punishment, as well as different contingencies he/she may otherwise never have been exposed to. The behaviors mentioned here, though non-exhaustive, are all considered cusps as they lead the individual to contact new experiences which would otherwise be outside of reach (Hixson 2004).

Within the context of behavior analytic intervention programs, some specific examples of cusps for young children may include: the reduction of behavior excesses, attending, cognitive, motor, imitation, academic, and language skills. In this sense, cusps which are of greatest relevance for a younger demographic correspond relatively closely to early developmental milestones. Examples of cusps for older children may include some of the ones listed above in addition to: social skills, self-help, daily living, and vocational skills. With this population, the focus often becomes teaching behaviors that will lead to further independence. In general then, if a child is demonstrating a large proportion of skills in a certain domain at or near age level, other domains will be prioritized, and a greater number of lessons will be developed to address this deficit area. Additionally, skills which constitute early prerequisites for the subsequent development of appropriate age-level skills, will also be prioritized (Hixson 2004).

A multitude of other variables also enter into the equation when making decisions related to prioritization and planning. For example, some additional considerations which must be taken into account when selecting which skills to target include: the importance of the development of a particular behavior (i.e., what is the extent of the behavior change, what later changes will the behavior change enable?), whether the development of a particular skill will expose the individual to new cusps as a result of the behavior change (e.g., when an increase in attending and a decrease in behavior excesses allows the child to contact an additional number of learning opportunities), whether the individual (assessed whenever possible) and other important individuals in his/her environment consider the behavior change important, as well as whether a behavioral trap (i.e., this refers to the transfer of stimulus control to a community of reinforcement existing in the organism's environment which can ensure the ongoing maintenance of skills as well as shape up new behaviors) can be set up to maintain the behavior change (e.g., attendance to preschool will help ensure the maintenance and development of more complex academic, play, social, and language skills). Bosch and Fuqua (2001) offer a systematic approach to both the identification and prioritization of cusps and the reader is referred to their article for a more detailed discussion.

Language and the acquisition of a sufficient and effective communicative repertoire is, quite arguably, the most important cusp, and the same problem of prioritization applies to teaching language. Following assessment, especially in the case of young children diagnosed with developmental disabilities, it is more often than not the case that a very significant deficit exists across all necessary skills required to become an effective speaker (i.e., expressive language) and listener (i.e., receptive language). Both constitute separate repertoires, and both are incredibly complex as they relate to the development of other higher-order skills (e.g., categorization, mathematics, academic skills, play and social skills, problem solving, behavior excesses, and independence) from which the vast majority of skills related to other developmental domains will be rooted. Thus, a more careful analysis of cusps must be undertaken when teaching language (Skinner 1957; Sundberg 2008). In the sections below, we will discuss the issue in further detail and offer up some practical suggestions for guiding these types of programming decisions.

Teaching Mands

As previously mentioned, the first goal of communication training is to give the child a functional way to express his or her needs. The mand is perhaps the most important of the verbal operants, as it benefits the speaker directly. It is usually one of the first to emerge developmentally, and can often lead to the acquisition of further language as well as immediate decreases in interfering behaviors. For this reason, the mand should be prioritized, emphasized, and taught early on in intervention. This can be accomplished by using a variety of communication modalities such as vocalizing, signing, the use of augmentative devices, or the use of picture exchange systems (Mirenda and Dattilo 1987). Vocal behavior is always the preferred method (Shafer 1993), but some children show great difficulties with vocal production and articulation, as well as vocal imitation (Smith and Bryson 1994), which could greatly delay the acquisition of functional speech and delay the child's cognitive progress. In these cases, either sign language or a picture-based system could be employed. Deciding whether pictures or signs should be used has been a matter of controversy among researchers and clinicians alike for a number of years now (Michael 1985; Shafer 1994; Sundberg and Michael 2001; Tincani 2004; Ziomek and Rehfeldt 2008). The debate lies in determining whether one system is superior to another in terms of rates of acquisition and the potential for emergence of vocal language (i.e., a cusp skill). While some research has pointed to the superiority of sign language over symbolic systems in terms of acquisition and accuracy (Potter and Brown 1997), other studies (Adkins and Axelrod 2002; Tincani 2004; Vignes 2007; Ziomek and Rehfeldt 2008) have suggested that children with autism acquire symbolic systems such as the Picture Exchange Communication System (PECS; Bondy and Frost 2001) quickly and with a high degree of accuracy. Thus, when choosing a mode of communication, clinicians should pay careful attention to a number of variables, including the child's motor skills, scanning abilities, accessibility and portability of the communication system itself, as well as the likelihood of having a verbal community that would be able to communicate with the child fluently utilizing the selected modality (Carr and Miguel 2013). It is important to note that the use of either signs or symbolic systems does not prevent a child from continuing to learn vocal behavior or speech. Thus, the use of symbolic systems may be an efficient and effective way of teaching functional communication to a child who otherwise lacks the ability to express his/her needs in an appropriate way (LeBlanc et al. 2009).

Once the mode of communication is selected, clinicians should decide what specific topographies or words to teach. Because many problem behaviors initially displayed by children diagnosed with developmental disabilities may have social and communicative functions (Durand and Carr 1985), it makes sense to select mand targets that would replace or serve the same function as problem behavior (Hagopian et al. 1998).

Many recent studies have focused on the selection of the communicative response and how this selection can influence the efficacy of training (Harding et al. 2009). Variables to consider when selecting the alternative response topography include: the amount of effort required, novelty, history of reinforcement with previous topographies, and preference. Functionally equivalent alternative communicative responses that require less effort than the problem behavior to obtain reinforcement are more likely to achieve four specific results: (1) they are likely to be acquired quickly, (2) they are likely to be maintained, (3) they are likely to lead to a more rapid decrease in behavior excesses, and (4) they are likely to contribute to the maintenance of low rates of problem behavior (Hernandez et al. 2007; Horner and Day 1991; Richman et al. 2001). The likelihood of an individual choosing to engage in the alternative communicative response is inversely proportional to the amount of effort required to engage in that response, relative to the problem behavior. In other words, the less effortful the response, the more likely the individual is to engage in that response. Therefore, the alternative response must require less effort compared to the problem behavior in order for the former to replace the latter. For this reason, mand topographies previously displayed by an individual should take precedence over novel mand topographies, even when existing mand topographies are associated with higher rates of problem behavior (Winborn et al. 2002). Since this intervention is highly individualized, results of preference assessments of mand topographies are idiosyncratic, with some individuals preferring to engage in vocal behavior or signs (Harding et al. 2009) and others indicating preference for methods such as pressing a microswitch (Falcomata et al. 2010).

Once functional mands have been taught, the client should then learn to mand for a variety of preferred items using single words across many settings and people. This is because it is more advantageous to the child, in terms of control over his/her environment to have a variety of one-word mands, than to have a limited number of mand sentences (LeBlanc et al. 2009). Clinicians should also avoid teaching abstract generalized mands such as “more” and “please” in the beginning of an intervention program since these mands are nonspecific. When learning these mands, the child learns to request whatever preferred item he or she wants, but only when the item is present. Therefore, the child becomes dependent on having the item in sight to mand. Additionally, this may discourage children to learn to mand using the item’s name (Barbera 2007).

Several studies on how to teach mands for items and information have been conducted (e.g., Sundberg et al. 2002; Lechago et al. 2010). One of the most studied procedures is called “interrupted chain” (Hall and Sundberg 1987) in which after learning to engage in a chain of behaviors (e.g., making a snack), materials needed to complete a step in the chain are made unavailable, therefore generating the ideal antecedent condition for teaching the behavior. For example, one may teach a child to serve himself/herself a bowl of ice cream, but withhold the spoon. This procedure has been recently adapted to teach mands for information such as who, which, where, and how (Lechago et al. 2010). For example, Lechago et al. taught participants to mand for a spoon utilizing an interrupted chain procedure targeting one skill. They subsequently assessed for the generalization of the specific mand taught (i.e., asking for a spoon) across multiple establishing operations[2] (EOs; Laraway et al. 2003)

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[2] As discussed previously in the text, motivating operations (MOs) have two distinct effects in that they (a) change the relative value of a particular stimulus, and (b)

by evoking the response in two different behavioral chains. Their results not only showed that all participants generalized the mand across EOs when the specific mand was evoked by chains of responding which required provision of a spoon for completion, but also that it is possible for new mand topographies to emerge following this type of training. Using this experimental arrangement, the authors were able to demonstrate that a specific mand form can be taught and generalized across different EOs without the need for additional training, and that the teaching of a specific mand topography may also lead to the development of additional mands.

Mand training opportunities can also be captured as opposed to contrived (Sundberg and Partington 1998, 1999; Barbera 2007). More specifically, when opportunities to mand are set up in such a way that the antecedent conditions are structured by the interventionist, we call these contrived. Examples include placing highly preferred items in clear containers that the child cannot open independently, setting these items in sight but out of reach, or providing only some of the pieces required to complete a preferred activity (e.g., puzzles). In these situations, opportunities are contrived as they are specifically arranged to set the occasion for the child to mand and receive reinforcement by establishing an EO. This method is exceptionally helpful in teaching a foundational repertoire consisting of mands for preferred and desired items. When naturally occurring opportunities are capitalized upon, however, these are considered captured. An example of this type of arrangement consists of blocking a child's access to an item *after* he/she has already initiated reaching for that item. This method allows one to guarantee an EO is in place and utilize the opportunity to teach manding. It is often regarded as being much more natural than the former strategy, as it is embedded throughout the course of whatever activities would typically already occur and appears to be more fluid. Mands for the cessation/removal of undesired or aversive stimuli are most appropriately taught using this method, so as to prevent the inadvertent establishment of inappropriate behavior excesses as a more effective means of achieving this outcome (LeBlanc et al. 2009). Usually, a combination of these two methods is utilized to help maximize the total overall number of learning opportunities presented and ensure that manding is strengthened in the behavioral repertoire.

In certain instances, a child may not necessarily have already learned the words required to mand, or may not yet produce these particular vocalizations. As mentioned above, the use of a symbolic system such as sign language or PECS can often act as a "bridge" to vocal production (Charlop-Christy et al. 2002). However, if a child is observed to produce vocalizations and to imitate, vocal mands can be shaped up through the use of transfer of stimulus control and errorless teaching procedures (Green 2001). Generally speaking, in these types of procedures, prompts that reliably evoke the desired behavior are used to occasion responding in a certain condition. A delay is then typically inserted between the presentation of the antecedent stimulus (which is the one intended to occasion responding) and the prompt (which is the one controlling responding). The delay is systematically and gradually increased until such a point that the response solely occurs in the presence of the antecedent.

So, when teaching a child to mand for a missing item necessary to make a snack (e.g., a spoon), the teacher can prompt the child to "say spoon" and deliver the spoon contingent on the correct vocalization. In this case, the child's response was solely occasioned by the clinician's prompt, but it also occurred in the presence of

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temporarily alter the frequency of any behavior, which has produced that stimulus in the past. These effects, however, can be categorized as either one of the two specific types of MOs. The establishing operation (EO) increases the value of a certain item and therefore also increases the frequency of the behavior leading to that item. For example, when one feels cold, warmth is more highly valued and will lead to any behavior which results in warmth, such as adjusting a thermostat, putting on additional pieces of clothing, rubbing one's skin, lighting a fire, etc. In contrast, the abolishing operation (AO) decreases the value of a stimulus as a reinforcer and results in the temporary reduction of any behavior associated with obtaining that item. Once one is warm, the value of warmth decreases and there will be a decrease and potential temporary cessation of any and all behaviors, which lead to warmth.

the right motivational variable (wanting the spoon), and produced the specific desired consequence (the spoon). With careful programming, the clinician can slowly delay his/her echoic prompt which would cause the child to eventually respond prior to the prompt, ensuring that the child's responding eventually comes under sole control of his/her motivation to obtain the item. This systematic delaying of a prompt is referred to as a "prompt delay procedure" (Cooper et al. 2007), and has been used to teach a variety of behaviors (Touchette and Howard 1984), and there are specific guidelines on how to use it to maximize its effectiveness (Karsten and Carr 2009). More generally speaking, these types of procedures can be used to "jumpstart" verbal operants that are weak in the repertoire by taking advantage of other operants that are consistently and reliably demonstrated.

Otherwise stated then, echoics can be capitalized upon as a prompting procedure to teach intelligible spoken mands. Once a robust repertoire of echoic behavior is established, spoken language eventually replaces the use of communication systems, as it generally requires less effort both in production and in portability, and is much more likely to come into contact with continued reinforcement across environments.

Teaching Echoics

As alluded to in the section above, the ability to imitate someone else's vocal behavior plays an important role in the development of other forms of verbal behavior (Hixson 2004; Horne and Lowe 1996; Lowenkron 1998). Typically developing children often learn to label items (tacts) when imitating their caregivers' labeling of a particular item in its presence (Horne and Lowe 1996). Additionally, when a child with disabilities is able to successfully imitate, then his/her vocabulary can be greatly expanded. Instead of having to slowly shape sounds into full words using differential consequences, the clinician is able to simply prompt the child vocally, by telling him/her what to say in a specific condition.

Because echoic behavior serves an important function in expanding the child's functional verbal repertoire, its absence is concerning to those attempting to develop vocal communication or speech. Over the years, many studies on how to teach vocal imitation were published (Kymissis and Poulson 1990; Young et al. 1994) and described in teaching manuals (Lovaas 2003; Sundberg and Partington 1998).

When children are nonresponsive to these procedures, clinicians may want to consider switching to a different mode of communication (symbolic or signs) while still attempting to teach vocal behavior in this context (Charlop-Christy et al. 2002). Alternative procedures such as stimulus–stimulus pairing (SSP; Smith et al. 1996) as well as the natural language paradigm (NLP; LeBlanc et al. 2006) can also be employed to jumpstart vocal behavior.

In the SSP procedure, the therapist models a target sound which can be a full word, or just a phoneme (e.g., "ba") and then gives the child a preferred item regardless of whether or not the child imitates. Repeated sequences of the target sound and access to the preferred item establish a close relationship along a temporal dimension (i.e., contiguity), turning the sound into a conditioned reinforcer which may lead the individual to produce that sound more frequently (Miguel et al. 2002; Smith et al. 1996). Although the method does not seem to produce consistent results (e.g., Carroll and Klatt 2008; Esch et al. 2005; Normand and Knoll 2006), some authors (Esch et al. 2009) have suggested that by ensuring that participants are attending to the experimenter, presenting the vocal response immediately followed by the edible, and presenting a nontargeted vocalization not followed by the presentation of the edible, may enhance the effects of the procedure.

As described by Charlop-Christy et al. (1999), the NLP procedure consists of having the clinician play with the child in a naturalistic setting such as setting up a multitude of toys and/or games on the floor. During play, the clinician offers a choice of three objects/toys and allows the child to make a selection. Once a selection is made, the clinician subsequently models appropriate play actions and related vocalizations (e.g., “vroom, vroom!” while rolling a car on the ground). Any child-directed attempt to vocally imitate results in immediate reinforcement; typically in the form of gaining brief access to the item selected. This same process is repeated, with the clinician modeling actions and vocalizations following each interchange. Over time, the clinician fades his/her vocalizations so that the stimuli which come to evoke the child’s vocal responding consist of the objects and actions in play. Additionally, the intelligibility and accuracy of the child’s utterances are typically shaped gradually through the use of echoic prompts (see the description of transfer of stimulus control procedures in the section on teaching mands above).

While the SSP seems to jumpstart vocalizations that can later be increased and placed under echoic control, the NLP directly teaches the echoic relation, as well as the mand. Both procedures can be implemented in a more naturally occurring setting such as play.

Teaching Tacts

There is no better strategy to increase vocabulary other than by teaching individuals to tact items within their environment. Additionally, tacts serve as the foundation for complex verbal repertoires (e.g., naming) as will be discussed later (Greer and Ross 2008). It is important to note that although we sometimes use the terms tacting and labeling interchangeably, tacts are defined as verbal behavior under the control of nonverbal stimuli (objects, actions, or properties). In other words, not all tacting looks like labeling. Entering an elevator full of people, for example, increases the likelihood of saying “Hello,” or something like it. In this case, the verbal behavior “Hello” is a function of the presence of people in the elevator (nonverbal stimulus), and thus fits the category of a tact. Differently than mands, tacts are reinforced by nonspecific consequences. When a child first says “dog” in the presence of a dog, the consequence is educational (Skinner 1957), in the sense that parents may acknowledge and praise the child for the correct label. Over time, children learn to discriminate between classes (dogs vs. cats) and generalize within classes (label all different dogs as “dogs”; Keller and Schoenfeld 1950).

Also, while mands permit the listener to infer something about the condition of the speaker regardless of external circumstances, tacts permit the listener to infer something about the circumstances regardless of the condition of the speaker (Sundberg 2007). So, tacts are extremely important to the listener as they extend his/her capacity to contact stimuli via the behavior of the speaker. For instance, an individual may be able to look through the window and say that it is raining (tact) to a listener who may not have otherwise obtained the information (e.g., perhaps the listener is too far away from the window to observe weather conditions). The fact that the listener now can appropriately act upon the environment (e.g., put on galoshes, a rain coat, or get an umbrella before going outside) as a result of the behavior emitted by the speaker, serves as a major reinforcer for the speaker’s tact. Actually, this is the main reinforcement for the tact in typically developing adults; while generalized reinforcement in the form of praise is usually more important when the behavior is being first acquired (Skinner 1957).

Although parents may directly teach tacts to typically developing children, most tacts are acquired incidentally after children learn to follow instructions and echo (Horne and Lowe 1996). Once a caregiver’s vocalizations reliably occasion the child’s echoic behavior in the presence of the object, and the caregiver provides appropriate consequences for the child’s echoic behavior, over time the object itself (without the caregiver’s vocalization) becomes sufficient to evoke the child’s tact (Horne and Lowe 1996). Thus, the establishment of strong listener and echoic repertoires may lead to the incidental learning of tacts (Greer and Ross 2008), and sometimes mands (Ribeiro et al. 2010), but this is not a reliable finding in children diagnosed with autism (Sprinkle and Miguel 2013; Whynn and Smith 2003).

Despite the fact that typically developing children often learn receptive discriminations (i.e., receptive language, listener responding) prior to tacting (i.e., expressive language, speaker responding), and that several books recommend teaching language by using a receptive–expressive (i.e., listener–speaker) sequence (e.g., Lovaas 2003), this recommendation seems to have little empirical support, and some very compelling evidence exists to show that the reverse sequence (teaching in a speaker–listener sequence) may be more efficient (Petursdottir and Carr 2011). More specifically, studies conducted examining the likelihood of transfer across the listener and speaker repertoires have found that accurate listener responding is more likely to emerge, *without the need for specific training,* following tact training, than vice versa (Whynn and Smith 2003; Sprinkle and Miguel 2013). This is of critical importance, as teaching utilizing this type of sequence may increase the efficiency of intervention by teaching more in less time. Thus, tact training plays a central role in early language intervention and should also be emphasized very early on in any program.

When training a child to tact, several additional strategies may be used. As with the mand, transfer of stimulus control procedures can be employed to shift control from an echoic to a tact (see the procedure described in the section on teaching mands above). Additionally, it is sometimes possible to capitalize on existing mands in that child's repertoire to occasion responding. This is referred to as a mand–tact transfer procedure (Barbera 2007; Sundberg and Partington 1998) and consists of capitalizing on behavior that is already trained to serve as a bridge to teach new behavior. Specifically, when utilizing this procedure, a mand is occasioned by presenting a preferred item that reliably evokes responding. Once the mand is emitted in the presence of the item, however, the interventionist delivers some form of generalized conditioned reinforcer as opposed to the item itself. Over repeated and subsequent trials, this allows for the transfer of stimulus control to additional stimulus conditions (i.e., a condition of aversive stimulation or deprivation for the mand, and the sight of the item for the tact), thereby freeing the operant from mand control. It is important to note here that great care must be taken to avoid the delivery of specific reinforcement when using such a procedure so as to not accidentally teach additional mands. Thus, the clinician must ensure that the tact comes under control of a discriminative stimulus, and not an MO.

Similarly, a reverse procedure can be used to teach mands. Briefly, training a child to tact preferred items can sometimes lead to mands (Wallace et al. 2006). In this case, however, the item tacted should also be the one delivered to ensure that the appropriate stimulus control is established (i.e., the mand comes under control of a relevant EO).

The use of mixed operant training (e.g., tact and mand trials) during intervention has also been suggested as a teaching strategy (Barbera 2007; Sundberg and Partington 1998). In this training format, trials of mands and tacts of the same response form (e.g., saying "cookie") are interspersed within the same session. However, while some research has suggested that this teaching strategy may be superior to teaching mands and tacts separately (Arntzen and Almås 2002; Carroll and Hesse 1987), these results are not always achieved (Sidener et al. 2010). Theoretically, the mixed verbal operant training is similar to multiple-exemplar instruction (Carr and Miguel 2013), which has been shown to be an efficient teaching strategy (e.g., Fiorile and Greer 2007). Though clinicians may choose to intersperse trials of mands and tacts (as well as other verbal operants), additional clinical research is needed.

Initial tact training should focus first on teaching children to respond to relevant stimuli, as these will be commonly encountered and talked about within the context of their natural environment. According to LeBlanc et al. (2009), this is typically done by targeting familiar and salient stimuli, and progressing from stimuli that are likely to be most salient and therefore simpler, to most complex. They suggest that children should be taught to tact items first in their three-dimensional form (e.g., preferred items, animals, letters, numbers, toys, food items, body parts, family members, etc.) prior to teaching additional tacts to two-dimensional representations (e.g., locations, community helpers, other important people in the environment, etc.). Next targets may subsequently include tacting the features or attributes of objects, expanding to familiar locations in and out of the home (e.g., bedroom, bathroom, living room, grocery store, school, etc.), and community helpers (e.g., police officer, cashier, fire fighter, etc.), and progressing on to more difficult targets such as functions of objects (e.g., scissors-cut, napkins-wipe, chair-sit, etc.), actions being performed (in pictures or in vivo, on self or others), classes or categories of objects, relational tacts such as prepositions (off/on, over/under, next to, between, etc.), descriptors (first/middle/last, short/tall, thick/thin, etc.), superlatives (small/smaller/smallest, long/longer/longest), and tacting private events (e.g., pain or discomfort in a certain area of the body, transient states such as hunger, etc.).

Teaching Intraverbals

The intraverbal is probably one of the broader categories in Skinner's framework as it encompasses a multitude of topographies under functional control of dissimilar verbal stimuli. These may include answering questions (e.g., saying "blue" when hearing, "What's your favorite color?"), associating words (e.g., saying "sad" when hearing "dying"), verbally categorizing objects and events (e.g., saying "table, chair, shelves" when talking about furniture), and translations (e.g., saying "car" when hearing "voiture"). The ability to respond to the verbal behavior of others is of utmost importance when learning conversational skills (Sundberg and Partington 1998), as well as other social and academic skills (Partington and Bailey 1993), so it is not surprising that the intraverbal is one of the verbal relations to have recently received the most attention.

While typically developing children may learn to intraverbally relate words due to the frequency with which they appear together (i.e., contiguous usage; Skinner 1957; Hart and Risley 1995), children with autism may need to be directly taught to do so. While simple intraverbals such as fill in the blanks (e.g., "3, 2, 1 …," "Ready, set …," "The wheels on the …," etc.) can be easily incorporated into a child's early programming, more complex forms of intraverbals such as question asking and answering will need to be taught once the child has already acquired a certain number of functional mands, tacts, and echoics (Barbera 2007). Even though intraverbal behavior may not always emerge following tact and echoic training (Miguel et al. 2005); these two verbal operants seem crucial in the teaching of intraverbal relations (Ingvarsson and Hollobaugh 2010). When teaching a child to answer social questions using echoic prompts, for instance, the therapist may present the question (verbal stimulus), "What do you wear on your feet?" and immediately provide an echoic prompt (i.e., errorless teaching) by saying "shoes." The child who can already imitate would then respond by saying "shoes" solely as a function of the echoic prompt. In this situation, then, stimulus control is exerted over responding through an additional stimulus (i.e., the prompt). Over subsequent trials, the therapist would present the question and progressively delay the presentation of the echoic prompt while allocating differential consequences for independent responses that precede the prompt (i.e., transfer of stimulus control; Karsten and Carr 2009), until no prompt is needed. In other words, independent responses result in a greater quality or magnitude of reinforcement than do prompted responses. The same skill can be taught using visual prompts by showing the child a picture of shoes after the question is asked. If the child can tact "shoes" when presented with a visual representation of shoes (i.e., a two- or three-dimensional stimulus), then initially the behavior would be solely under control of the visual prompt until a prompt delay with differential reinforcement procedure is adopted, and stimulus control is transferred to the appropriate source (i.e., the question).

Although early studies have suggested that visual stimuli may be more efficient as prompts (Finkel and Williams 2001; Ingvarsson and Hollobaugh 2010), others (Ingvarsson and Le 2011) have found auditory prompts to be superior in terms of trials to criterion (i.e., requiring fewer trials until mastery of the intraverbal skill). It is, however, possible that the success of a particular prompt procedure is a function of individual learning histories, as children seem to require fewer trials to acquire new intraverbal responses with a prompt type that was most recently used compared to a prompt type that had not recently been used (Coon and Miguel 2013). A particular child's learning style (i.e., "visual learner" vs. "auditory learner"), therefore, may be a function of his/her individual learning history and be subject to change depending upon the stimulus conditions and contingencies contacted. Thus, practitioners who are becoming newly acquainted with a child or student may benefit by obtaining information about that individual's history of successes or failures with particular prompting methods before considering which methods to use with that individual. However, if such information is unavailable, it may be possible to probe prompt effectiveness and/or create a reinforcement history with a method that is better adapted to the individual's learning environment. For example, when vocal prompts are considered distracting to other learners in the environment (e.g., such as in a classroom setting), a practitioner may select an alternative prompting method (e.g., tact or textual) and establish a reinforcement history with that method.

As suggested earlier, there is abundant literature on how to teach a variety of intraverbal relations, all of which involve the presentation of a stimulus (prompt) that already predictably exerts some control over the behavior, concurrently or immediately following the presentation of the target verbal stimulus. Echoic (i.e., auditory; Ingvarsson et al. 2007; Pérez-González et al. 2007; Petursdottir et al. 2008; Secan et al. 1989; Watkins et al. 1989), textual (i.e., written; Krantz and McClannahan 1993; Krantz and McClannahan 1998; Sarakoff et al. 2001; Thiemann and Goldstein 2001), and tact (i.e., visual; Braam and Poling 1983; Goldsmith et al. 2007; Luciano 1986; Miguel et al. 2005) prompts are then systematically faded until the target verbal stimulus alone evokes the behavior.

Of note, while intraverbals seem to play an obvious role in conversation, many important problem-solving skills require the use of intraverbal behavior at either the overt or covert level (Skinner 1974). Examples of such common situations include: solving a complex math problem, getting the ingredients from the kitchen cupboards for a recipe, remembering a list of items, etc. Typically developing teenagers and adults usually engage in intraverbal responses at a covert level to help them solve the problem at hand or complete the task required. Similarly, typically developing children are often observed to use intraverbals on a more overt level (e.g., when asked, "How old are you?" the child may mediate his/her response by counting out the number on his fingers prior to responding). Children diagnosed with ASDs, on the other hand, often need to be taught this vitally important skill.

In two recently published studies (Kisamore et al. 2011; Sautter et al. 2011), the authors found that after being taught to use intraverbals as a strategy to mediate responding, participants completed tasks that they were not previously able to perform in baseline measures. More specifically, in the study conducted by Sautter et al., children were asked to tact several items belonging to a particular category (e.g., farm animals, sea animals, zoo animals). Initially, children were provided with certain rules to guide their responding: They were told to use a problem-solving strategy, which consisted of self-prompting through the use of intraverbal chains. The provision of this rule alone was not sufficient to generate correct responses. However, once this strategy was modeled, and prompts provided to teach the strategy, all participants showed immediate improvement in categorization responses. In the study conducted by Kisamore et al., visual prompts were utilized to teach participants to use a visual imagining strategy. As in the first study, however, children did not show an increased accuracy in responding to categorization questions until after they were taught to use this strategy through modeling and prompting. In both studies, participants' accuracy of responding increased significantly and immediately following the training of verbal- and visual-based mediation strategies to answer categorization questions. Additionally, once established in the repertoire, all prompts were successfully faded, and the use of the trained strategies alone was sufficient to maintain accurate responding. These studies suggest that intraverbal behavior serves a fundamental role in mediating complex performance.

Intraverbal relations also exemplify how verbal behavior can be multiply controlled (Skinner 1957; Sundberg 2007). While simple intraverbal behavior such as saying "go" may be a function of a single verbal stimulus (i.e., hearing "Ready, set … "), more complex intraverbals such as saying "steak" when hearing "What did you eat for dinner?" requires control by multiple variables (i.e., conditional discrimination; Axe 2008), given that the response "steak" is a function of the convergence of two stimuli "eat" and "dinner" (Sundberg 2007). Many children with autism fail to acquire complex intraverbal repertoires, despite having learned mands, tacts, and listener skills. While these children may be able to respond to simple questions, they cannot answer difficult questions, describe experiences, or stay on topic during conversations (Sundberg and Sundberg 2011). Even though mand, tact, listener, and simple intraverbal repertoires seem to serve as prerequisites for learning complex intraverbals (Axe 2008), clinicians must specifically teach children to respond to multiple stimuli from the start of intraverbal training so as to prevent participants to attend to only one rather than multiple features of a compound verbal stimulus (e.g., When hearing "What did you eat for dinner", the child may respond to the stimulus "eat" but not "dinner"). Axe (2008) and Sundberg and Sundberg (2011) discuss many strategies that may be helpful to clinicians attempting to teach complex intraverbals; however, few of them have been empirically validated for this purpose.

Textual Behavior and Comprehension

Skinner defined textual behavior as responses emitted in the presence of printed words or textual stimuli *without the need for understanding* what is being said (Skinner 1957). In practice, textual behavior is only one of the skills taught as part of a program to develop reading comprehension (de Souza et al. 2009). An early reading ability that illustrates this notion is responding to sight words.

Comprehension is usually trained and assessed using the matching-to-sample procedure (Sidman 1971), in which participants are taught in the presence of a dictated sample to select the corresponding printed word from an array of at least three. Participants are also taught to select, in the presence of the same dictated word, its corresponding picture. As an outcome, participants not only perform the trained tasks (e.g., select printed words and pictures in the presence of dictated words) but also are able to select pictures in the presence of printed words and vice versa, suggesting that dictated words, pictures, and printed words become substitutable for one another, or have the same meaning (Sidman 1994). In many of these studies, participants were also able to read aloud, as well as tact the pictures (e.g., Sidman et al. 1974). In this case, reading is more than textual behavior given that the auditory product of the participant's textual response (the sound produced when reading) serves as a discriminative stimulus for selecting the object which that word represents. Thus, it can be said that participants are reading with understanding, as they are behaving as both speakers and listeners (Greer and Ross 2008; Horne and Lowe 1996; Sidman 1994; Skinner 1957).

Behavior analysts have produced ample research in the area of reading comprehension, and a well-developed technology is readily available (de Souza et al. 2009; Mackay 1985; Saunders 2011). In general, researchers suggest a program that initially teaches children to select the correct letter given its dictated name, name individual letters, as well as match each letter to itself (identity matching; Saunders 2011). Although letter discrimination may lead to discrimination of printed words, this outcome is not consistent (Stromer et al. 1993); thus, practitioners may have to teach word discrimination, usually by teaching spelling (Mackay 1985). Participants may also need to be taught how to discriminate speech, abstract phonemes, and select printed words and corresponding pictures in the presence of their dictated names (de Souza et al. 2009; Mackay 1985; Saunders 2011).

In addition to being used as a tool for teaching reading comprehension, the matching to sample procedure has been shown to be quite an efficient method for teaching a variety of skills in clinical settings (e.g., Groskreutz et al. 2010; Keintz et al. 2011; LeBlanc et al. 2003; Miguel et al. 2009). For instance, Miguel et al. (2009) taught two preschoolers with autism to select pictures and printed words given their dictated names via matching to sample. The pictures were previously used as part of participants' activity schedules (McClannahan and Krantz 1999). Following training, participants could accurately follow a printed activity schedule by completing the depicted task in the presence of their printed words. Additionally, they could read these printed words with comprehension, as they were able to match printed words to pictures without explicit training (Sidman 1971). As mentioned above, the matching to sample procedure may produce a variety of novel skills after carefully selected training sequences are implemented (Stromer et al. 1996). These procedures seem, however, to be most beneficial to those participants who can react to stimuli as both speakers and listeners, or in other words, can *name* (Horne and Lowe 1996; Miguel and Petursdottir 2009).

Naming and Symbolic Behavior

Behavior is considered verbal only when it affects a listener that in turn reacts by reinforcing the behavior of the speaker. But the speaker himself/herself is also a listener as he/she can also be affected by his/her own behavior (Skinner 1957). We say that the vocalization "dog" for instance, is a tact if it is under the control of a nonverbal stimulus (i.e., the sight/presence of the actual dog) and produces mediated reinforcement by a listener who understands what the word "dog" means. Thus, the listener may be affected by the word "dog" (auditory stimulus) by engaging in conventional behavior such as orienting toward a dog, or "seeing," "smelling," or "hearing" a dog as conditioned perceptual responses (Skinner 1953). In other words, even if the listener is not in the presence of a dog or the visual representation of a dog, upon hearing the word "dog" he/she may think of a dog. Additionally, the speaker, who can also hear himself/herself say "dog" reacts to his/her own vocalizations the same way (as a listener). In this sense, then, there is always a listener present, as the same person serves as both listener *and* speaker, whether it be to his/her own vocalizations or another's. It is only when an individual behaves as both a speaker and a listener that he/she may be considered verbal (Carr and Miguel 2013; Greer and Ross 2008; Horne and Lowe 1996; Skinner 1957), as it is only then that one can say the individual "understands." However, speaking with understanding means more than just reacting as a listener, as the spoken (written, signed, etc.) words must be substitutable for the objects they represent. For example, the word "dog," the printed word "dog," and the actual dog must be substitutable for one another, or members of the same equivalence class (Sidman 1994). Without this relation with other objects/events, words would lack any meaning (Horne and Lowe 1996; Sidman 1994), and be considered nonverbal (Barnes-Holmes et al. 2000).

The term "naming" has been used to describe the integration of both listener and speaker behaviors. We say that someone "demonstrates" naming when the reinforcement of a listener relation is accompanied by the emergence of a speaker relation, without the need for training, or vice versa (Miguel and Petursdottir 2009). When naming is taught to children who are missing it, they can then learn both the listener and speaker functions incidentally through observation (and without direct instruction from others; Greer and Longano 2010). In the absence of naming, the mastery of the listener and speaker responses in the presence of the same stimulus requires separate instruction. For instance, if a child is taught to point to a stimulus while hearing its name (i.e., a dog), he/she may not be able to later behave as a speaker by tacting the stimulus (e.g., Whynn and Smith 2003; Sprinkle and Miguel 2013).

Therefore, the capacity to *name,* or react as both a speaker and a listener seems to be a critical and necessary cusp skill for those individuals learning to communicate. It also makes it possible for children to come to learn language incidentally, as well as read and write effectively

(Fiorile and Greer 2007; Greer et al. 2005; Greer et al. 2007).

Studies have shown that children with and without autism who did not initially tact objects after learning how to receptively discriminate them did so following a history of training to point to and tact a variety of exemplars (multiple exemplar training; Fiorilie and Greer 2007; Greer et al. 2005). Some practitioners have, in fact, recommended interspersing tact and listener trials during training (LeBlanc et al. 2009; Sundberg and Partington 1998) rather than adhering to the more commonly proposed receptive-before-expressive instructional sequence. Although not evaluated empirically, this method of interspersal may be likely to produce a generalized naming repertoire (Petursdottir and Carr 2011).

Another strategy for promoting the acquisition of naming includes teaching echoic (vocal imitation) responses during receptive discrimination training. Although not directly evaluated with children with autism (Petursdottir and Carr 2011), this strategy may lead to the development of a tact since the child's speaker behavior is being reinforced in the presence of the selected object, along with the listener response.

The presence of naming has also been associated with the development of equivalence classes or categorization (Horne et al. 2004; Horne et al. 2006; Lowe et al. 2002; Lowe et al. 2005; Mahoney et al. 2011; Miguel et al. 2008). So, for a child to comprehend that the printed word "dog" and the picture of a "dog" are substitutable for one another (i.e., have the same meaning), he/she would have to behave as both speaker and listener toward these stimuli. In other words, the child needs to be able to select both stimuli (i.e., printed word and picture) when hearing the spoken word "dog" as well as label both stimuli (i.e., printed word and picture) as "dog." Additionally, the child would also have to vocalize "dog" (textual behavior) when seeing the printed word, and upon hearing himself/herself say "dog," engage in conventional listener behavior (e.g., orienting toward a dog/picture of a dog, thinking of a dog, conditioned seeing of a dog, etc.). Recent studies conducted with children with autism have shown that when participants can behave as listeners but not as speakers, or as speakers but not as listeners, they are unable to behave similarly to stimuli (i.e., categorize or relate stimuli) that are supposed to have the same meaning (Miguel and Kobari-Wright 2013; Sprinkle and Miguel 2013).

These studies have important applied implications given that the skill of sorting or matching objects that have the same meaning or belong to the same category (e.g., sorting pictures of maps of northern and southern states) may develop with no direct training when children learn to tact pictures and objects with a common category name, *as long as* they can also engage in listener behavior (i.e., by selecting these pictures when given their names). Procedures on how to teach naming and produce untrained categorization have been fully described elsewhere (Miguel and Petursdottir 2009), and the reader is referred to these sources. Additionally, an applied technology specifically developed for teaching listener behavior is also available (Green 2001) and will not be discussed here.

Naming, therefore, is an important cusp skill as it has several further widespread changes. Further, each of the changes it causes has the potential to propagate even more change through the development of additional skills (Hixson 2004). Once naming is established, children usually demonstrate not only improved acquisition of speaker and listener skills, but also the untrained transfer of skills between these two repertoires (Greer and Ross 2008). This is particularly important for children diagnosed with autism, as naming is one of the most essential underpinnings observed in typically developed learners (Horne and Lowe 1996). Additionally, from a clinician's perspective, when transfer between repertoires is observed to occur readily, much time and effort can be saved and priority can be shifted to teaching other vitally important skills. Second, the development of naming lends meaning to language. Otherwise stated, naming has the potential to facilitate the formation of equivalence classes, allowing members within these classes to become substitutable for one another, an important factor in reading comprehension (Stromer et al. 1996). When one understands that the printed word dog is equivalent to the spoken word "dog" and the actual dog, it is said that the concept is "understood." Third, as a function of transfer between speaker and listener repertoires, as well as comprehension, when failures in conditional discriminations are observed, they can be rectified through the establishment of naming (Eikeseth and Smith 1992). This is a critically important skill, and a cusp itself, as the majority of stimulus situations we encounter as adults require that conditional discriminations be made (Green 2001). Last, but not the least, naming promotes the development of other important nonverbal skills such as categorization (Miguel et al. 2008), which is considered a fundamental process in making sense of our surrounding environment (Barsalou 1992).

Conclusion

We leave our readers with two cautionary notes. The first is that the information presented in this chapter is nothing more than a brief summary of methods for teaching the most basic verbal operants. We did not discuss the listener relation or the autoclitic (Skinner 1957), both of which are essential to the development of an adequate communicative repertoire (Carr and Miguel 2013; Sundberg 2007). While the use of the information contained here may be a good starting point, it should not be regarded as either a complete representation of the current state-of-the-art behavior analytic approach to language development or a detailed account of teaching procedures (Sundberg and Partington 1998). The reader is strongly encouraged to further pursue information by referencing the resources cited. To present the entire breadth of information the field of behavior analysis currently holds on language development and intervention would far exceed the scope of this chapter.

The second pertains to the use of the term "the verbal behavior approach" (Barbera 2007; Carr and Firth 2005), which has been used to refer to the application of Skinner's (1957) analysis to the design of language intervention programs. This sometimes results in confusion and misunderstanding as the vernacular implies a new technology. This is not a new approach. It does, however, constitute a movement away from a more traditional perspective, which assumes that language is an independent entity and that all communication consists primarily of the transmission of ideas (Miguel 2009, 2011). Those ascribing to the traditional perspective commit themselves to the development and application of teaching curricula emphasizing when to teach rather than how, diluting the potency and the contributions of a behavioral conceptual analysis of language. On the other hand, when language is conceptualized and treated like all other behavior, the net result is a parsimonious, yet powerful analysis, which necessarily leads to an efficient and effective language intervention allowing those with language impairments to communicate meaningfully and with understanding.

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Social Skills and Play in Children with Autism

17

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Keywords
Social · Play

Social skills refer to the behaviors that allow an individual to interact with others in a mutually reinforcing way and to adapt those behaviors to different situations (Schopler and Mesibov 1986). Individuals with autism often display profound deficits in social behavior (e.g., Kanner 1943; Rimland 1964; Rutter 1978) and one of the defining characteristics of this disorder is an unwillingness or inability to engage in social interactions (American Psychiatric Association 2000). Researchers and practitioners have developed numerous interventions designed to address these deficits. The present chapter reviews social skills deficits commonly demonstrated by children with autism, the importance of improving the social skills of children with autism, and interventions that are commonly used to improve the social skills of children with autism.

Social Skills and the Developing Child with Autism

Social skills deficits may be apparent as early as infancy. Unlike neurotypical infants, infants with autism may not reach out in anticipation of being picked up, mold to their parents' bodies when held, or seek out or give affectionate gestures (e.g., hugs and kisses; Charlop-Christy et al. 1998). Another deficit that first appears during infancy in children with autism is a lack of eye contact and the demonstration of gaze aversion (American Psychiatric Association 1994). Infants with autism may also display less attachment to their parents and exhibit little or none of the separation anxiety commonly observed in neurotypical children (Weiss and Harris 2001). More specifically, infants with autism may seem content to be left alone and may cry when approached by parents or others. As children with autism get older, these social deficits continue and other deficits may emerge. Young children with autism often fail to demonstrate joint attention behaviors (e.g., following another's gaze or gesture, alternating gaze between a person and a stimulus, gesturing towards a stimulus) or respond to social stimuli (Bass and Mulick 2007; Clifford and Dissanayake 2008; Dawson et al. 2004; Leekam and Ramsden 2006; Rutherford and Rogers 2003). Furthermore, children with autism may fail to

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imitate others. Neurotypical children imitate the actions of others, including verbal behavior such as speech sounds. However, many children with autism have to be taught even simple imitations like clapping hands or standing up (Weiss and Harris 2001). This lack of ability or interest to imitate others interferes with the development of a variety of social skills learned through the observation and imitation of adults or peers.

An additional area of impairment seen in young children with autism that interferes with early socialization is an atypical and delayed progression of play skills (Bass and Mulick 2007). Children with autism have been found to engage in less play and develop play skills later than neurotypical children and other children matched on mental age (Bass and Mulick 2007; Minor 2003). When children with autism do play, they tend to spend more of their time on less complex or solitary play than neurotypical peers (Libby et al. 1998; Weiss and Harris 2001). Further, the play exhibited by children with autism often lacks creativity and tends to be limited to preferred toys. Often, the behavior is not really play at all but stereotypic or repetitive behaviors (e.g., staring at the wheels of a car as they turn, lining up objects). This lack of play limits children with autisms' ability to participate in peer interactions because much of the social interactions of children center around play.

Social deficits become even more apparent as children with autism enter elementary school. School-age children with autism often fail to respond to or initiate interactions with peers. When children with autism do initiate interactions, it is often in an atypical or inappropriate way (e.g., excessive touching to gain attention or standing too close to the peer), and they may have difficulty sustaining the interaction. Sustaining interactions can be particularly difficult because many children with autism are unable to or uninterested in talking with others. Many children with autism fail to develop functional speech (Rimland 1964; Rutter 1978), and those children who do acquire language often only demonstrate short requests (e.g., "I want cookie") or simple responses (Schreibman 1988). Children with autism often demonstrate a lack of eye contact, social problem solving ability, empathy, and awareness of social cues (e.g., body language; Schreiber 2011). These deficits make it difficult for children with autism to participate in extended and successful social interactions and may exacerbate the severe social withdrawal already exhibited by many children with autism (Charlop-Christy and Kelso 2003).

The Importance of Improving the Social Skills of Children with Autism

Social skills are critical to daily functioning. Further, research has shown that social interest and social skills development are among the strongest predictors of the long-term adjustment and functioning of individuals with autism (Matson and Swiezy 1994). Children with autism who learn to seek out and enjoy social interactions with others and understand appropriate social rules are more likely to live and function independently.

There is also evidence that social skills deficits negatively impact the child's functioning across developmental domains (e.g., social, academic, and behavioral). Often, children with a lack of or less developed social skills tend to be less popular with and perceived negatively by peers (Matson and Sweizy 1994). The resulting lack of social interactions is believed to negatively affect other areas of functioning by decreasing children with autism's learning opportunities and developmental support (Koegel and Frea 1993). In sum, poor social skills are related to more behavior and mental health problems and lower levels of academic achievement. Together, this research indicates that social skills are critical to the success and long-term functioning of children with autism. Therefore, it is critical that treatments effectively address the social skills deficits of children with autism and improve their ability to initiate and navigate social interactions.

Improving the Social Skills of Children with Autism

It has been recommended that children with autism have access to individual and small group social skills services (National Initiative for Autism: Screening and Assessment (NIASA) 2003).

To maximize the utility of these services, it is important that each child's program be individualized to target appropriate skills with empirically based treatments that enable that child to succeed. The following sections discuss issues to consider when selecting social skills to target and the treatment approaches that can be used to do so.

Selecting Social Skills for Treatment

There are several issues to consider when selecting the social skills to target in a child's program (Matson and Swiezy 1994). First, it is important to select social skills that are functional and useful to the child (Cooper et al. 2007). In other words, a child's program should target the skills that will allow him or her to be as successful and independent as possible in his or her natural environments. Aside from the obvious practical value, these behaviors are also more likely to be appreciated and reinforced by others. Naturally occurring reinforcement contingencies increase the likelihood that the child will continue to demonstrate the skills following treatment and generalize the skills to other behaviors, settings, and interaction partners (Matson and Swiezy 1994).

It is also important to target skills that are congruent with and respectful of the child's family's beliefs and culture (Harry et al. 1999). Families and cultures have different opinions regarding what behaviors are appropriate for children, and it is important to consider the norms of a child's social environment when selecting social skills to target. Considering these contextual variables increases the likelihood that the skills targeted will be acceptable and sustainable for the family and other individuals in the child's life (Albin et al. 1996; Harrower et al. 1999). Therefore, it is crucial to include parents in program planning.

Selecting appropriate social skills to target also requires consideration of a child's developmental level. It is important to reference normative developmental information (i.e., the age when an average neurotypical child achieves certain skills) when deciding which social skills are relevant to a child (Harris and Ferrari 1983). For example, it is developmentally appropriate to teach a 1-year-old child to make eye contact or engage in joint attention, but it is not appropriate to teach the child to initiate and sustain a conversation.

When targeting a skill, it is also necessary to identify any prerequisite behaviors and target them first. Successful programs typically break complex social behaviors into smaller, more manageable steps determined by the child's current developmental and chronological level (Cappadocia and Weiss 2011). For example, engaging in a reciprocal conversation requires that the child be able to ask and respond to questions. These skills can be taught individually and then paired together to teach the more advanced skill of engaging in extended reciprocal conversations. Unfortunately, very few comprehensive assessments and curricula currently exist for selecting social skills (see chapter on designing curricula in this volume).

Treatment Approaches

A variety of procedures have been used to teach social skills to children with autism. Like the skills targeted, it is important that the utilized intervention be individualized to the child. Whenever possible, the selected treatment approach should be designed to build upon the child's existing skills and strengths while addressing areas of deficit. Additionally, the treatment approach should be consistent with the child's family's beliefs and values (Harry et al. 1999). Finally, it is of paramount importance that selected treatment approaches have empirical support (i.e., published studies in peer-reviewed journals showing that the approach improves the social skills of children with autism). Selecting treatment approaches that have been shown to improve the skills of at least some children with autism increases the likelihood that the intervention will effectively improve the skills of the current child with autism. The remainder of this chapter describes a number of behavioral treatment approaches that have been used to improve the social skills of children with autism. It is important to note that this is not an exhaustive list, but rather discusses the interventions that are most commonly referred to in the social skills literature.

Visual Strategies

At least some children with autism appear to have trouble attending to and understanding auditory information and are better able to understand information that is presented visually (MacDuff et al. 1993; Pierce and Schreibman 1994; Tissot and Evans 2003). More specifically, children with autism spectrum disorder have been found to score lower than neurotypical peers on verbal memory tasks, but scored similarly to neurotypical peers on visual tasks. Visual strategies build upon this strength by using visual prompts (e.g., pictures, videos, written words) to facilitate skill acquisition (Quill 1997; Tissot and Evans 2003). Common visual strategies for social skills include video modeling and scripts.

Video Modeling

Video modeling has been used to effectively teach children with autism a variety of social skills. In video modeling, the child watches short, filmed clips of a model (i.e., peers, siblings, adults, or the child him or herself) engaging in the targeted behavior and is then given the opportunity to demonstrate the skill (Bellini and Akullian 2007). The child continues to watch the video until he or she consistently demonstrates the targeted behaviors.

Video modeling has been effective in teaching a wide range of social behaviors to children with autism (Charlop-Christy et al. 2000). For example, Nikopoulos and Keenan (2004) used video modeling to teach three children with autism to initiate an interaction by vocally asking an adult to play. In this study, the children observed a neurotypcial peer say “Let’s play” to the experimenter and then subsequently engage in reciprocal play. Subsequent to viewing the video, the children increased both their initiations as well as their reciprocal play.

In the first video modeling study with children with autism, three children with autism who only spoke in short utterances were taught to engage in conversation with phrases of up to eight words per exchange (Charlop and Milstein 1989). Each exchange consisted of a response to another’s question and a reciprocal question to the interaction partner. All children learned to engage in conversational exchanges and continued to do so up to 15 months after completing the intervention. Following intervention, participants were also able to have conversations on other topics, with unfamiliar conversation partners, and in untrained settings.

Nikopoulos and Keenan (2007) also taught social sequences to children with autism through a video modeling procedure. More specifically, the children were taught to make social initiations (e.g., “Let’s play”) and to then engage in object imitation (e.g., picking up a ball). Results indicated that the participants increased their social initiations and also engaged in more reciprocal play, peer imitation, and less isolated object manipulation following intervention. Further, gains generalized to other peers and were maintained 1 and 2 months following intervention.

Video modeling has also effectively increased more abstract skills, like social cognitive skills. For example, Charlop-Christy and Daneshvar (2003) used video modeling to teach three children with autism perspective taking (i.e., the ability to determine another person’s mental state to predict behavior). After the video modeling intervention, all three improved their ability to perform the perspective-taking task. The children also demonstrated gains with untrained stimuli and responses.

There is also evidence that video modeling can successfully target multiple skills simultaneously. One study used video modeling to target verbal (i.e., verbalizations and intonations) and nonverbal (i.e., gestures and facial expressions) socio-communicative behaviors (Charlop et al. 2010). Three children watched videos of adult actors modeling all four of these behaviors. All of the children increased their demonstration of all three behaviors after watching the video only three or four times.

Space does not permit a comprehensive review of video modeling studies, but the procedure has also been used to increase a variety of other skills, including the cooperative play (Charlop et al. 1989), reciprocal pretend play (MacDonald et al. 2009), and play-related statements (Taylor et al. 1999) of children with autism.

Several advantages are thought to contribute to the effectiveness of video modeling in teaching social skills to children with autism. First, the videos can focus on the targeted behaviors, which eliminate irrelevant stimuli that are often present in the natural environment (McCoy and Hermansen 2007). This is believed to increase the likelihood that the child with autism will focus on the relevant cues (Charlop-Christy et al. 2000; Krantz et al. 1991). Additionally, video modeling allows for standardized and frequent presentation of the modeled behavior (Ferraioli and Harris 2011), which may speed acquisition. Finally, video modeling is believed to increase the child's motivation to participate in the intervention. Children who seem uninterested in other learning activities have been found to request and enjoy watching video modeling tapes (Ferraioli and Harris 2011).

Scripts

An additional visual strategy that has successfully taught social skills to children with autism is script and script-fading procedures. Script interventions utilize written cue cards or audio recordings to prompt children to use appropriate language (Brown et al. 2008). Once the child consistently demonstrates the language with the script, it is gradually faded starting from the last word. For example, a child is initially shown a written script with "I played catch" written on it. Once the child consistently reads this phrase, the written prompt fades to "I played," then to "I," then a blank piece of paper, and finally the paper is removed so that the child is independently demonstrating the targeted behavior.

Scripts have been used to target a number of social behaviors. For example, Woods and Poulson (2006) used written or audio scripts to increase the social initiations three children with autism directed towards neurotypical peers. Each child was provided with at least ten scripts that were related to school activities and objects. Once the scripts were introduced, all of the children demonstrated more social initiations. The study did not fade the scripts from the treatment setting; however, the participating children also increased their initiations to peers during sessions in a different setting without the scripts.

Scripts have also been used to teach conversational speech to children with autism. One study utilized a script-fading procedure to increase the verbal initiations and conversational speech of three children with autism (Brown et al. 2008). Scripts were presented during simulated shopping trips. All children demonstrated the scripted speech and demonstrated these and novel utterances after the scripts were faded. Further, the children talked about untrained objects and increased their verbal interactions during actual shopping trips.

Charlop-Christy and Kelso (2003) used scripts to teach three boys with autism to engage in conversations about familiar activities (e.g., school, favorite pastimes, watching television). Each child's script was composed of seven lines. The first and last lines were statements to initiate and conclude the interaction and the other lines consisted of a responding statement and a question. During training, a therapist would say their lines and immediately prompt the child to read the appropriate cue card. After the child read the card, he was told to repeat the scripted line while making eye contact with the therapist. At the end of each training session, the child was given a reinforcer for sitting nicely, reading the cards, and paying attention. All three boys learned the scripted conversations quickly and continued to use them once the scripts were removed. In addition, the boys also increased their conversational speech about new topics, with new interaction partners, and in new settings.

Script and script-fading procedures are a useful and efficient teaching strategy. Scripts can be developed, prepared, and implemented relatively quickly with a number of interaction partners in different environments. Practically, scripts are inexpensive, as the interventionist can simply write the developed lines on a piece of paper or note card. At face value, some may object to the notion of teaching children with autism to recite scripts because rote memorization of scripts is, in itself, a problematic behavior of many children with autism. One might be concerned, therefore, that using scripts with children with autism may encourage memorization, rather than real-life, flexible social skills. The generalization data in the research described above, however, demonstrates clearly that the vast majority of children who receive scripted interventions learn to engage in varied, flexible, generalized social interactions as a result. That is, although counterintuitive, script interventions actually produce the generalized ability to apply social language to a variety of situations, not "scripted" or rote responding.

Self-Management

Self-management programs have been used to teach a variety of skills to children with autism, including social skills. Self-management programs typically begin by training individuals to monitor their own behavior (Deitchman et al. 2010; Southall and Gast 2011). The treatment provider (e.g., therapist, teacher) identifies a specific behavior that the child should increase or decrease and sets a goal for how many times this behavior should occur in a specified period of time or during a certain activity (e.g., five initiations in 30 min or taking ten turns during a board game). Further, the child with autism is taught to record the occurrence or nonoccurrence of the behavior of interest and to self-evaluate the amount of behavior recorded. When a child achieves the predetermined goal, the child gives him or herself a reinforcer or reports to a treatment provider to gain access to a reinforcer.

Self-monitoring has been shown to effectively increase the social skills of children with autism (Lee et al. 2007; Southall and Gast 2011). One study taught four children with autism to use a wrist counter to monitor appropriate responses to questions in a clinical setting (Koegel et al. 1992). The children were able to learn to monitor their own behavior and increased their appropriate responding in the clinical setting. In addition, the children were able to monitor their responses in untrained home and community settings. The use of self-management procedures increased their appropriate responses in these settings, as well as decreasing disruptive behaviors.

Another study used a self-management program to increase the variability of verbal responses and play skills (i.e., pretend play or drawing) in three children with autism (Newman et al. 2000). During baseline, the children demonstrated high rates of restricted and repetitive behaviors (e.g., repeating the same verbal answer or play sequence). During intervention, the children were initially prompted to correctly monitor their behavior and were then given the opportunity to do so independently. The children did not learn to monitor their behavior with a high degree of accuracy, but still demonstrated significantly more variability in the target behaviors.

Stahmer and Schreibman (1992) implemented a treatment program that included self-management to increase the appropriate play of three children with autism. The children were first trained to discriminate between appropriate and inappropriate play behaviors and then to monitor their own play behaviors during gradually lengthened intervals. As in the previously discussed study, the children were not always accurate in their self-management. However, the children still increased their demonstration of appropriate play and continued to do so during unsupervised play sessions.

These studies indicate that self-management can effectively increase the social and play behaviors of children with autism. Self-management programs are advantageous for several reasons. First, increasing an individual's awareness of his or her own behavior is often sufficient in changing the behavior (Cooper et al. 2007). Also, self-management programs are designed to enable the child to run his or her own program. This has clinical and practical implications. Clinically, a child can independently apply mastered self-monitoring skills across different settings, stimuli, or people in his or her everyday life. Treatments that do so may also promote generalization because they teach the individual how "to generalize" learned skills across their lives (Stokes and Baer 1977). Practically, self-management programs minimize the involvement of treatment providers (e.g., clinicians, teachers, parents; Lee et al. 2007). This may be especially useful in classroom settings where teachers supervise numerous students and educational programs and may not have the time to implement more extensive programs.

Social Skills Groups

Social skills groups have also been conducted to address a variety of social skills deficits (Reichow and Volkmar 2009; White et al. 2007). Social skills groups implement social skills interventions with multiple children with autism. These programs generally target a number of social skills over a number of group sessions. The specific procedures utilized in these group programs depend on the curriculum, and many of these programs include additional treatment components (e.g., parent training, supplementary individual therapy).

There is preliminary evidence that social skills groups alone may be sufficient in increasing the social skills of individuals with autism. For example, Tse et al. (2007) conducted a social skills group for high-functioning and verbal adolescents with autism spectrum disorders. Groups consisted of seven–eight adolescents each and for an hour and a half a week over 12 weeks. Sessions used role-play and psychoeducational and experiential techniques to target a range of social skills, including eye contact, interpreting nonverbal cues, initiating, maintaining, and ending conversations, and coping with teasing and bullying. Forty-six parents completed standardized questionnaires before and after their child participated in the program. Their data indicated that their children demonstrated statistically significant improvements on social behaviors and decreased problem behaviors. Thirteen of the participating adolescents also completed a survey after participating in the group. Many of the adolescents reported that they liked the group, and that they had improved social skills such as having a conversation and handling teasing. These findings indicate that social skills groups may improve the social skills of individuals with autism, but additional research utilizing more objective measures of participant progress is needed.

Kroeger et al. (2007) examined the effectiveness of a social skills group that used video modeling and prompting to teach young children with autism social and play skills. The children improved their social skills (i.e., social initiation, response, and interaction behaviors) more than a matched control group of children who participated in group sessions without the video modeling and social skills instruction. This study indicates that children with autism can learn social skills within social groups. However, most research examines the effectiveness of social skills groups in combination with other intervention strategies.

The Junior Detective Training Program was designed to teach social skills to children with Asperger's Syndrome (Beaumont and Sofronoff 2008). This program consisted of group social skills sessions, a computer program, parent training sessions, and teacher handouts. Parents reported that children who participated in the program gained more social skills than children with autism who were randomly assigned to a waiting list.

The Program for the Education and Enrichment of Relational Skills (PEERS) was developed for adolescents with autism spectrum disorders (Laugeson et al. 2009). This program focused on increasing the adolescents' understanding of common social rules and skills (e.g., conversation skills, peer entry and exiting skills, navigating arguments, good sportsmanship). Children participated in small group sessions that targeted these and other skills using empirically supported strategies (modeling, role-playing, feedback) and brief one-on-one instruction. Parents also participated in training sessions intended to prepare them to facilitate their children's use of the acquired skills. According to parent report, the adolescents who participated in the treatment program made more gains in their knowledge and demonstration of social skills and had friends visit their home more often than a matched control group. These studies indicate that social skills programs that include group instruction can effectively increase the social skills of individuals with autism spectrum disorder. However, because the program included other treatment components, it is not possible to determine the extent to which the observed gains are due to the social skills groups alone.

The social skills group at the Claremont Autism Center has also delivered promising results (Charlop and Hye in progress). In this program, children with moderate-to-high functioning autism are grouped with neurotypical peers for weekly, 2 h session. During each session, the children participate in several different types of activities that are commonly found in the children's natural environment (e.g., school recesses, classroom activities, and extracurricular activities like sports, boy or girl scouts, or other peer interactions). Children participate in outdoor activities including athletic games such as kickball, softball, and handball, outdoor games with less structured rules such as tag, red light/green light, and hide and seek, and brief periods of free play. Children also engage in a variety of indoor activities that require communication and cooperation such as building a robot with a partner or creating and performing small-group skits. All of the activities are designed to target a range of socio-communicative and play behaviors. The children learn about teamwork, competition, and cooperation and how to take turns, communicate ideas, navigate disagreements, and to be patient with less articulate children. Pull-out treatments like video modeling are also provided to improve nonverbal and verbal social initiations and other social and play behaviors. Preliminary data examining the effects of this program are encouraging, and data are continued to be collected at the time of writing this.

Targeting social skills during group interventions is beneficial for several reasons. First, the group setting resembles many naturally occurring social situations, as many of the children's interactions (e.g., at school or in the community) will involve multiple children. Additionally, group settings allow the children to practice learned skills with different peers. Teaching skills in an environment similar to naturally occurring settings and having the children use these skills with multiple interaction partners are believed to facilitate the generalization of learned skills (Stokes and Baer 1977). However, a significant amount of further research is needed to determine the ideal combination of group versus individual social skills instruction, and how this ratio is best determined for each individual child with autism. In addition, further research is needed to determine the optimal teaching procedures that should be included in social skills groups. Most social skills groups that are currently offered to parents of children with autism are not centered on evidence-based teaching procedures, and it is therefore unknown how effective most such programs are.

Parent Training

Parent training refers to any program that aims to improve parents' ability to obtain an effective treatment package for their child (National Research Council 2001). This goal can be achieved by increasing their ability to identify and obtain appropriate services or to directly deliver treatment to their child. Below, we review research on interventions that enable parents to facilitate their children's social skills' acquisition.

Parents have been taught to implement a number of empirically supported interventions and their implementation of these interventions has been found to improve their children's social skills. For example, parents have been trained to implement script and script-fading procedures (Reagon and Higbee 2009). After training, the parents were able to implement a script-fading procedure targeting their children's social initiations, and all three children with autism increased their demonstration of scripted and unscripted initiations.

Vismara et al. (2009) instructed parents to use empirically supported, naturalistic developmental and behavioral teaching strategies with their recently diagnosed toddlers with autism. Parents participated in 12 weekly, hour-long training sessions. During training sessions, a therapist reviewed past techniques with the parents, explained new techniques to the parents and modeled these with the child, and provided the parents with feedback on their use of strategies while interacting with their child. Generally speaking, parents were successfully trained to implement the targeted strategies. Additionally, all eight children exhibited more functional language, and all but one child engaged in more imitative behavior. Overall, gains were maintained several weeks after the completion of the intervention.

Parent training is considered a critical component of autism treatment (Matson et al. 2009). Parents and other family members are central to child development because of the large amount of time they spend with their children and the large degree of control parents have over their children's environment. Enabling family members to incorporate learning opportunities into their daily routines is one way to increase the intensity of services that children receive (Seung et al. 2006). This is especially critical given the importance of early and intensive treatment and the grievous lack of qualified providers of such treatment (Eldevik et al. 2006; National Research Council 2001; Lovaas 1987). It should be noted, however, no scientific evidence yet exists to suggest that parents can be the sole providers of early intensive behavioral intervention for children with autism.

Peer-Mediated Strategies

Peer-mediated strategies are commonly used to increase the social skills and interactions of children with and without disabilities (Goldstein et al. 1992). Peer-mediated strategies typically involve training neurotypical peers to facilitate interactions with children with autism (Wang et al. 2011). For example, the peers may be taught how to prompt or reinforce appropriate social behaviors demonstrated by children with autism.

Peer-mediated strategies have been found to effectively increase the social interactions of children with autism and neurotypical peers. For instance, one study taught neurotypical peers about autism and strategies for interacting with these children and responding to aggressive behavior (Roeyers 1996). Children who participated in ten play sessions with the trained peers demonstrated more gains in social engagement (e.g., time spent interacting with the peer, responding to initiations, and appropriate play) than children who did not participate in the ten play sessions. Additionally, some of these increases generalized to play sessions with another neurotypical peer or child with disabilities.

In another study, Goldstein et al. (1992) instructed neurotypical peers to pay attention to, talk about, and acknowledge the verbal and nonverbal social behaviors of four children with autism and one child with autistic characteristics. After training and with ongoing adult prompting, the neurotypical peers used their newly learned strategies when interacting with the children with autism or autistic characteristics. Additionally, four of the children with autism increased their social interaction when peers used these strategies with them.

Another intervention, Keys to Play, used peer training, adult prompting, and visual cues to increase the play initiations of four preschool children with autism (Nelson et al. 2007). Once the intervention was implemented, the children with autism increased their initiations. As the children increased their initiations, they also spent more time engaging with peers and demonstrated more advanced types of play.

It is worth noting that many peer-mediated interventions also include adult support and prompting (e.g., Goldstein et al. 1992; Nelson et al. 2007). The extent to which trained peers use taught strategies and that this affects the social behavior of children with autism is not clear. In fact, there is some evidence that peer training without additional adult support is not sufficient for improving the social behaviors of children with autism or promoting the maintenance and generalization of the targeted behaviors (DiSalvo and Oswald 2002). There is only strong empirical support for peer-mediated approaches with adult involvement.

Peer-mediated interventions are a useful component in comprehensive social skills interventions for children with autism. The goal of any treatment is to prepare the child to successfully navigate their natural environments, and for children with autism this means interacting with neurotypical peers. Including peers in interventions allows the child to practice skills with appropriate peer partners and may facilitate skill generalization to these natural settings. In addition, it is possible that including peers as interventionists may help make treatment more efficient because it may require less adult involvement than traditional adult-mediated social skills training. However, a significant amount of further research is needed to directly address these potential benefits.

Conclusion

Children diagnosed with autism demonstrate considerable deficits in social skills, and these deficits have a significant negative impact on their development and outcomes into adulthood. Social skills are therefore considered a critical area of intervention. Numerous interventions have been developed to improve the social skills of children with autism. The present chapter described many of these interventions, including video modeling, scripts, social skills groups, peer-mediated strategies, and parent training. While existing research indicates that these interventions successfully increase the social skills of at least some children with autism, each child's treatment should be individually tailored to his or her needs and strengths. Each child's intervention should target useful social skills that would most promote the child's independent functioning with treatment packages that build off of the child's current abilities and that are consistent with the family's beliefs and culture. Further, it is important to continually monitor the child's progress to ensure that ongoing interventions effectively facilitate his or her progress. Providing children with autism effective evidence-based, individualized social skills treatment is likely to improve their overall outcomes, helping them to become independent and successful adults.

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18

Teaching Cognitive Skills to Children with Autism

Jonathan Tarbox and Adel C. Najdowski

Keywords
Perspective taking · Executive functions

Autism spectrum disorders (ASD) are characterized by deficits in language, socialization, and the presence of restricted interests (American Psychiatric Association 2013). Cognition is an area of functioning that is critical to everyday functioning across all three of these areas. A large amount of research has documented cognitive deficits in individuals with ASD, in terms of general intellectual disability and specific areas of cognition, in individuals with or without intellectual disability. The topic of intellectual disability in ASD has received ample attention elsewhere and will not be the focus of this chapter. Instead, we will address particular areas of cognitive functioning as behavioral repertoires that are amenable to intervention. We begin by discussing basic philosophical differences between cognitive and behavioral approaches to the topic of cognition, not merely for scholarly interest but because doing so will lay the groundwork for how cognition can be researched and intervened upon behaviorally. Next, we review the burgeoning area of research into behavioral intervention for cognition in ASD. Finally, we dedicate a significant portion of the chapter to discussing future directions for research on teaching cognitive skills to children with ASD.

Conceptual Background for a Behavioral Approach to Cognition

Basic Philosophical Assumptions

There is a long-standing split between behavioral and cognitive branches of psychology that persists in strong form today. There are likely many reasons for this split but one of the fundamental sources of disagreement lies in the ontological assumptions that each branch holds in terms of what phenomena exist to be studied, as well as the epistemological assumptions each branch holds in terms of how those phenomena are to be studied. In terms of ontology, cognitive psychology is built on the assumption that unobservable mental or neuronal events exist and are causally responsible for behavior that is readily observable. Therefore, cognitive psychology is essentially the study of how mental or neuronal events cause organisms to behave in interaction with their environment. Behavior analysis is built on the assumption that mental events do not exist outside of the physical world and that, whatever

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they are, mental events cannot be reduced to neuronal events. According to a radical behavioral view of the universe, mental events (insofar as they actually exist) are events taking place in the physical world and consist of private behaviors and private stimuli. Therefore, behavior analysis is the study of how behavior evolves in its interaction with the environment. Neuronal events are not considered irrelevant; they are simply not included in the science of behavior analysis. They can certainly be studied when one combines behavioral science with neuroscience, but this would then be the study of the interaction of behavior, environment, and neuronal events. Neuronal events are not mental events; they are neuronal events.

Another fundamental point of departure between behavioral and cognitive psychology is the issue of reductionism. A foundational assumption of behavior analysis (and most natural sciences) is that the events that one studies cannot be reduced to anything more fundamental. Behavior cannot and need not be reduced to a lower level. It would be interesting to study the physiology at work when an individual plays the piano, for example, but it would not tell us anything about piano playing as a learned behavior, it would simply tell us about physiology. Similarly, with complex cognition, behavior analysis assumes that all we know is that individuals engage in complex behaviors when interacting with complex environments. The only way to understand these behaviors is to study them and their interaction with the environment. There is no utility, nor indeed any scientific basis, for creating hypothetical unobservable mechanisms to explain these behaviors. First, there is no empirical basis for doing so. Second, it is not fruitful because still another explanatory scheme must be invented to explain the mechanism.

Cognitive psychology, on the other hand, is built upon the notion that complex behavior can be understood by inventing unobservable hypothetical mechanisms which are responsible for the behavior. For example, why does a person recall auditory information on a test of auditory memory? Because the information was stored in their phonological loop. Various scholars within cognitive psychology appear to differ to the extent to which they engage in hypothetical mechanism creation metaphorically—as in, someone recalls information *as though* they had a phonological loop which stored it—or whether they believe the mechanism *actually exists* somewhere in the physical world. Of course, the only place such mechanisms could be guessed to exist is in the brain, but cognitive mechanisms have yet to be found in the brain. The only thing found in the brain is tissue and electrical activity. Hard drives, sketch pads, loops, and other storage devices have yet to be uncovered. In behavioral perspective, they will never be uncovered because the methods by which they were invented were fallacious from the beginning.

Philosophers of science such as J. R. Kantor (1953) point out that it is useful for all sciences to carefully examine the origin of the assumptions and constructs that make up the science. Ideas that have clearly nonscientific origin, such as coming from religion, metaphysics, art, and popular culture, should be eliminated, leaving only those that are the result of directly studying the events that the science studies. At the heart of this position is the assumption that natural science studies events in nature and nothing else. The practice of inventing hypothetical explanatory constructs in cognitive psychology falls into the "else" category, as it came from the traditional religious perspective of humanity comprising the spirit (unobservable inner world) and the flesh (behavior).

Behaviorism's fundamental insistence on studying only events in the natural world and nothing else (i.e., no hypothetical cognitive mechanisms) has led the vast majority of society to a false belief regarding behavior analysis: Behavior analysis excludes the world of the mind. This caricature of behaviorism is nearly 70 years out of date but is still ubiquitous. Behavior analysis does not deny the existence of the mind; it denies the existence of invented hypothetical mechanisms. B. F. Skinner's (1945) perspective, which has come to be known as radical behaviorism, proposes that behaviorism include *all mental events* which consist of real, natural phenomena. Indeed, Skinner insisted that virtually all mental events include behavior and stimuli which must be studied in behavioral psychology. For example, thinking, problem solving, imagining, day dreaming, remembering, worrying, categorizing, and reasoning are all things people *do*. They are psychological events which involve a large amount of complex behavior. Much of these behaviors are not directly observable to others, and so they have come to be known as private behaviors. However, the status of a behavior or a stimulus as public versus private is irrelevant to whether it should be studied in the science of behavior analysis. The full realm of human endeavor must be included in a comprehensive science of psychology (Skinner 1953).

The radical behavioral philosophical position described here likely appears foreign to many readers, and it is highly unlikely that a brief introduction to a book chapter will fundamentally change the way a reader views the events that comprise the subject matter of psychology. However, even if one abhors the basic philosophical assumptions of radical behaviorism, a radical behavioral perspective on cognition has something else to recommend it: It is inherently practical. The traditional cognitive approach to a particular topic is to construct a hypothetical unobservable explanatory mechanism, and then collect empirical data on observable behavior that can be interpreted to support one's model. In the best case scenario, orderly data are collected that allow for coherent and consistent interpretations that support one's model. But since the mechanisms which are believed to cause the behavior that actually matters clinically can never, by definition, be contacted, such a model can produce but little of clinical utility. A radical behavioral approach to the same problem would be to start with questions such as these: What behaviors must the individual engage in to be successful? In response to which stimuli must these behaviors occur? In what general contexts must these behavior–environment interactions be readily available? And most importantly, what learning history establishes these abilities? Regardless of one's basic philosophical perspective, research that is guided by answering these questions can be successful in solving practical problems of cognitive deficit.

The remainder of this chapter will describe emerging areas of research that have begun to do this. The field of behavioral approaches to cognition in individuals with ASD is still in its infancy, but the initial results are encouraging.

Complex Skills as Generalized Operant Repertoires

It is common in psychology to distinguish between simple behaviors versus cognitive abilities. From the most fundamental radical behavioral standpoint, this distinction is illegitimate—both always involve organisms engaging in behavioral interactions with environmental stimuli. However, what distinguishes simpler repertoires that are commonly referred to as behavior by the general community from complex behavioral repertoires commonly referred to as cognition is the degree of complexity of the behavioral repertoire. Perhaps the most important feature of this complexity is the fact that these repertoires demonstrate properties referred to as "emergence," "generativity," and "productivity." That is, the behaviors occur under conditions other than those in which the behaviors were learned. Indeed, a hallmark of any genuine cognitive ability is that it is not merely directly trained or memorized behavior. It is an ability or concept that can be applied in a flexible and adaptable way in new circumstances. For example, if one learns to reason cause-and-effect relations among events, one can now do so across a large variety of events, in a large variety of settings, and in the presence of a large variety of people, all of which were absent when the skill was originally learned. The same is true for planning, problem solving, perspective taking, self-management, and categorizing, among many other cognitive abilities.

Cognitive abilities that can be applied under circumstances other than those in which they were directly trained are called "arbitrarily applicable derived relational responding" in the relational frame theory (RFT) research literature. A full conceptual treatment of RFT is beyond the scope of this chapter and is readily available elsewhere (Rehfeldt and Barnes-Holmes 2009), so only a cursory description, adequate for the purposes of this chapter will be provided here. RFT is a theory of cognition that states that cognition consists largely of the behavior of relating events. Of course, there are many ways in which humans relate events in their daily lives. Two or more events can be similar, they can be different, they can be related in terms of a variety of comparisons (e.g., more/less, bigger/smaller, better/worse, taller/shorter, etc.), in terms of temporal relations (e.g., this happened before that), in terms of causal relations (e.g., A caused B, B was caused by A), in terms of categorical relations (e.g., apples are a type of fruit, fruits are a kind of plant, etc.), and in terms of perspective relations (e.g., I versus you), among others. RFT proposes that the cognitive activity of relating stimuli in each of these ways is learned operant behavior. In addition, each of these abilities is generalized operant behavior, learned via a history of multiple exemplar training (MET). Most importantly, the defining feature of generalized operant behavior is that it occurs in situations other than those present during training—it is "arbitrarily applicable," in the sense that the learner can apply the repertoire in novel, untrained situations that bear no physical similarity to those present during training.

The strength of treating cognitive abilities as generalized operant behavior is that it does not rely on invented unobservable, inoperable mechanisms, but rather makes specific, testable predictions regarding how these abilities can be trained and tested. If a particular cognitive ability is generalized operant behavior, it should be teachable through MET. We will now consider research in which that tactic has been used.

Research Review

As described previously, a relatively small amount of research has been published on behavioral interventions for cognition in individuals with ASD, although very little research of any kind has been published on successful intervention for cognition in ASD. The small amount of existing research will be reviewed below, followed by a discussion of a variety of directions for future research.

Working Memory

Working memory is the cognitive ability to keep information online and process it a short time later (Klingberg et al. 2005). Working memory is implicated in virtually every aspect of daily life, and working memory function is positively correlated with a large variety of meaningful outcomes, including numeracy and literacy achievement and long-term academic success (Alloway and Alloway 2010). Children with ASD have documented deficits in working memory (Hill 2004), so it seems likely that intervention is needed in this area. However, constructing intervention approaches on the basis of the existing research literature on working memory is difficult because most current models of working memory are hypothetical and refer either to general regions of brain structure or to hypothetical mechanisms which have never been directly observed (Baddeley 2000). In either case, until surgical or pharmacological interventions are invented which can act directly on these mechanisms (which seems unlikely), these models are of little practical utility for remediating working memory deficits. Of course, all episodes of working memory involve behavior occurring in relation to environmental stimuli. Therefore, it seems reasonable that such behavior should be amenable to improvement through MET. A recent series of three experiments have evaluated this possibility.

In the first experiment, Baltruschat et al. (2011a) used MET to improve performance on a "counting span" task in three children with ASD. The task involved presenting stimulus cards that contained quantities of shapes. When each card was presented, the child was asked to count and report the number of shapes on the card. A series of such cards was presented and at the end of the series, the child was asked, "Which numbers did you count and in which order?" and a correct response consisted of the child reporting the correct quantities and in the chronological order in which the cards were presented. Positive reinforcement of accurate responding to multiple exemplars of the task produced an increase in accurate responding for all three children. More interestingly, the improvement in accuracy generalized to a task involving different shapes and different quantities and maintained after positive reinforcement was discontinued.

In the second experiment in the series, Baltruschat et al. (2011a) further investigated the effects of MET on working memory by investigating a different test of working memory, a "complex span" task, and in three different children with ASD. The complex span task involved presenting stimulus cards that depicted objects that were either edible or inedible. When each card was presented, the experimenter asked the participant a classification question ("Can you eat it?") to serve as a distracter, after which the participant was required to answer yes or no, and then another such card was presented. At the end of the sequence of cards, the experimenter asked the participant, "Which objects did you see?" and the child was required to recall them in the correct order in which they were presented. Again, accurate responding on the task was positively reinforced across multiple exemplars and improvements in accuracy were observed for all three participants. Two participants had difficulty initially and were prompted to vocally rehearse the name of the objects while performing the task. This resulted in an increase in accuracy for both participants, and both were then required to gradually decrease the volume of their rehearsal until it was merely lip movement, and finally with no movement at all. At this point, participants were directed to "Say the names of the objects in your head" and accuracy remained high for both participants. This procedure was adapted from B. F. Skinner's conceptual analysis of how overt verbal behavior may gradually become conditioned into private verbal behavior labeled as thinking by the general community (Skinner 1974). After MET was complete, positive reinforcement was discontinued, and participants were tested on a complex span task that involved a different classification response ("Can you wear it?" instead of "Can you eat it?") and with different stimuli. Accuracy remained substantially higher than baseline for all participants, demonstrating both generalization and maintenance.

In the third experiment in the series, Baltruschat et al. (2012) investigated the effects of MET on a "digit span" working memory task. During this task, random series of letters (excluding series that spelled common words) were vocally presented to participants, for example "Q-L-M-E," and participants were then asked, "Tell me what letters I said in reverse order" and a correct response required participants to recall each letter in the reverse sequence to that in which they were presented. Again, positive reinforcement of multiple exemplars was used to increase accuracy. For two of the three participants, positive reinforcement produced substantial increases in accuracy. For the third, less consistent improvements in accuracy were produced, so a differential reinforcement system implemented with token reinforcers was used. During the token system, each correct response earned the child one token and four *consecutive* correct responses earned four tokens, thereby resulting in delivery of the backup reinforcer. Errors resulted in removal of all tokens. This system resulted in a differential reinforcement contingency in which the backup reinforcer could only be earned if four consecutive correct responses occurred. Accuracy then increased and stabilized. When MET was complete, reinforcement was discontinued for all participants, and participants were then tested for generalization by using only letters that had not been present during training. Accuracy remained substantially higher than baseline for all participants, thereby demonstrating both maintenance and generalization.

Taken together, the three experiments on MET for improving performance on working memory tasks in children with ASD provide initial evidence that working memory deficits may be amenable to treatment via behavioral intervention, and MET in particular. Perhaps the most encouraging findings of the studies were continuation of maintenance after reinforcement and generalization to untrained stimuli for all participants, suggesting improvements in the overarching repertoires involved in working memory tasks, not merely rote memorization of particular tasks or behaviors. The studies are not without their limitations, however. They were intended as translational studies providing initial applications of proven behavioral procedures to a new problem of clinical significance; they were not treatment studies. Much more research is needed on how to translate these findings into clinical interventions that produce durable changes in outcomes of importance in the daily lives of individuals with ASD.

Metaphorical Reasoning

Metaphors are a form of nonliteral language that are commonly used in everyday speech. It has been estimated that the average person contacts up to four metaphors per minute in daily conversation (Garner 2005). It is likely that merely through common usage and through contacting metaphors repeatedly in particular contexts that one may come to respond to them appropriately. However, to actually *understand the meaning* of a metaphor, a relatively complex form of reasoning is required. A metaphor consists of calling a thing something that it is not. By definition, there is a property that is shared between the two things, and this shared property constitutes the meaning of the metaphor. For example, one might state of someone else that "He is a rock." Of course, one does not literally mean that the person is a rock. However, the person might be particularly consistent and steady in his commitment to a particular pattern of behavior (e.g., athletic exercise, work, etc.). The shared property between the person and a rock may be consistency or strength. Therefore, to actually understand the meaning of the metaphor, one must be able to derive this shared feature.

A significant amount of research has documented deficits in nonliteral language in general and metaphors in particular in individual with ASD (MacKay and Shaw 2004). However, few or no previous studies have attempted to teach individuals with ASD to understand metaphors. One recent study used MET to teach three children with autism to understand novel metaphors (Persicke et al. 2012). A metaphorical statement generally consists of calling an object something other than what it literally is. For example, upon seeing a particularly fast runner, one might say, "He is a rocket!" As discussed above, metaphors have meaning for the speaker and listener because there is some attribute that the two stimuli share (in this case, both the runner and the rocket are *fast*). In RFT perspective, understanding a metaphor involves relating each stimulus to its own attributes (an example of hierarchical relating), and then relating each of the attributes of one stimulus to those of the other (Stewart and Barnes-Holmes 2001). Most of the attributes will differ (relations of distinction), aside from the one that gives meaning to the metaphor. In the example above, the runner has the attributes of being human, moving fast, and running, whereas a rocket has the attributes of being a vehicle, making fire, and moving fast. The shared attribute is fast movement, and so these two similar attributes relate to one another in terms of coordination or symmetry. Therefore, solving a novel metaphor involves engaging in relating behavior of all of these sorts, culminating in identification of the attributes that are similar, thereby identifying the meaning of the metaphor (e.g., "When you say that runner is a rocket, you mean he is really fast").

Persicke et al. (2012) began teaching this sequence of behaviors by explaining it to participants, that is, by providing rules for how metaphors can be solved. Therapists then provided opportunities for practice across multiple exemplars, with positive reinforcement for correct responding and immediate descriptive feedback for incorrect responding. For one of three participants, this alone produced large and consistent increases in correct identification of novel metaphors. For the other two participants, a visual aid was added, in which participants were prompted to write the name of the two stimuli contained in the metaphor (e.g., runner and rocket), and then write three attributes of each in a list below it. Participants were then prompted to draw a line that connected the single attribute that was shared by both stimuli, thereby identifying the meaning of the metaphor. For both participants, the addition of the visual aid resulted in rapid increases in correct responding and generalization to untrained metaphors. During post-training, the visual aid was absent, reinforcement was discontinued, and participants were tested on untrained metaphors, and all three participants continued to perform substantially better than in baseline, thereby demonstrating maintenance and generalization to untrained metaphors. In addition, anecdotal reports indicated that two of the three participants began creating their own metaphors, a repertoire that was never targeted during intervention.

Understanding Sarcasm

Sarcasm is a form of nonliteral ironic language in which what is said is the opposite of what is meant. Sarcasm is prevalent in daily language, with estimates of up to 8 % of daily conversational utterances (Gibbs 2000). A significant amount of research has documented deficits in irony and sarcasm in individuals with ASD. These deficits are not surprising, given the fact that many individuals are "overly literal" in their use of language, that is, people with ASD tend to say what they mean—something rather uncommon in the daily verbal interactions of typically developing individuals. Although this overly honest quality is laudable, the inability to understand and therefore respond appropriately to the sarcastic language of others could have serious detrimental effects on social functioning. For example, if a child shoots a basketball and misses and a peer says sarcastically "Wow, nice shot," a successful social response on the part of the shooter requires that they understand that the person making the sarcastic comment was not being sincere, that is, they did not really mean that they thought it was a nice shot. Responding as though the peer was giving a sincere compliment will make the person with ASD look gullible and therefore potentially a target for more teasing and/or bullying.

Despite the documented deficits in understanding sarcasm in the ASD population, and the clear social implications they have, few studies have attempted to teach the skill. One recent study used MET to teach children with ASD to identify and respond appropriately to sarcastic comments made by others (Persicke et al. 2012). The experimenters first gave a rule describing sarcasm, such as "Sometimes people say the opposite of what they really mean. This might mean they are being sarcastic. If someone is being sarcastic, you shouldn't act like they really mean what they are saying. Sometimes it works better to laugh or make another joke." Experimenters then presented multiple exemplars of sarcastic comments during conversation and gave participants immediate feedback on their reactions to it. Training began with repeated practice in a contrived manner and gradually progressed to more and more natural settings until the participants were responding appropriately to sarcastic comments made in the course of natural everyday conversation, in which it was impossible for the participants to determine whether they were even being trained or evaluated any longer. Furthermore, generalization was obtained to completely novel, untrained sarcastic comments and correct responding persisted in the absence of any contrived feedback.

Perspective Taking

Perspective taking refers to a very large and complex repertoire of behaviors, and a very large amount of developmental and cognitive research has documented deficits in perspective taking in individuals with ASD, most of which was conducted in the area of work referred to as "Theory of Mind" (Baron-Cohen 2000). Despite the hundreds of studies published on documenting perspective-taking deficits in children with autism, very little research has been published on effective treatments for perspective-taking deficits. Space does not permit a full treatment of this topic here, but the existing treatment research will be briefly described and a broader range of perspective-taking behaviors will be discussed later in the future research section of the chapter.

Knowing and beliefs Two studies have been published that used video modeling and MET to teach perspective taking to children with ASD (Charlop-Christy and Daneshvar 2003; LeBlanc et al. 2003). Both studies included the unexpected transfer task (aka, "Sally–Anne Task"). In this task, children are shown a pretend sequence in which one puppet (Sally) puts her ball in a box and then leaves the scene. While she is gone, and therefore cannot see what is happening, the second puppet (Anne) moves the ball to a different location (a basket). Sally then returns to the scene and the experimenter asks the child with ASD, "Where will Sally look for her ball?" The correct response, of course, is that she will look in the box, the location where she last saw it, since she was not present to see Anne move her ball and therefore does not know the ball is in a different location (the basket). Children with ASD often fail to distinguish between what they have witnessed (i.e., Anne moved the ball) and what Sally had witnessed. That is, they are not able to identify that someone else has a different sensory experience than their own, based on whether the other person is physically present or not. Therefore, a common error is to report that Sally will look for her ball where Anne moved it, because the child with ASD witnessed the move, even though Sally did not.

In both studies, video models were made that depicted others observing and talking through what was happening during the unexpected transfer task. Children were then trained on multiple exemplars using these videos. After training, children were able to pass the test and showed some degree of stimulus and response generalization. These two studies were a promising first step toward effective instruction for teaching perspective taking to children with ASD. Passing the unexpected transfer task appears to require several component skills: identifying that Sally is physically absent, identifying what she saw or did not see based on her physical location, identifying where she will think her ball is, based on what she saw and did not see, and predicting where she will look for her ball based on where she thinks it is located. The two studies described above likely taught all of these skills simultaneously; however, it was not the purpose of the studies to isolate or identify which skills were necessary and/or absent in the participants.

Visual perspective taking In a subsequent study, one particular component of the complex skills that are contained in the unexpected transfer task was isolated and taught: identifying what someone else can see based on the direction of their eye gaze (Gould et al. 2011). In this study, MET was used to teach children with ASD to follow the direction of others' eye gaze and to therefore correctly answer questions about what the other person sees. The intervention was effective and produced generalization to untrained stimuli; however, no programming was done to encourage generalization from contrived table-top teaching to the natural environment, and therefore, participants had difficulty with the skill in completely natural contexts. This result was not surprising and merely emphasizes the need to include programming for generalization to the natural environment, or merely teaching skills in natural settings to begin with.

Deception It is often said that children with ASD are overly literal and deception may be difficult because it is a form of verbal interaction in which something other than the literal truth is said. The ability to understand deception is crucial to successful social functioning. Parents of children with ASD often report that their children are "easily fooled" because they assume that other people are speaking the literal truth. Therefore, children with ASD can be the targets of bullying. For example, a bully might say to a child with ASD, "The teacher told me that I can have your toy," or "It's my ball, so I get to have two turns and you only get to have one." If the child with ASD is not capable of judging whether the bully is lying, he or she may have little recourse other than to give the bully what he or she wants.

One recent study used MET to teach children with autism to identify when others were lying to them (Ranick et al. 2013). Children were taught to identify two types of lies: (1) lies told to take possessions away from them and (2) lies told to exclude them from activities. Treatment began by telling the participants a rule that described why people might lie to them. For example, "A lie is when someone says something that isn't true or real. Sometimes people might lie to you because they want to exclude you or because they want to take your stuff. Let's practice and see if you can figure out when I am lying and when I am telling the truth." Experimenters then presented multiple exemplars of lies and true statements. Participants were asked to identify the lies and to resist them. For example, if an experimenter said, "I get to take two turns because I'm a girl," the participant was prompted to respond with something like "No, that's not true. Everyone gets one turn." Accurate responding was praised and errors (failing to detect when the experimenter was lying) were given immediate corrective feedback. MET continued until participants demonstrated generalization across untrained lies and across peers who were not included in training.

Successful social functioning requires not only responding to lies as a listener, but occasionally, to use them as well. "White lies" are a classic example of socially appropriate deception. Parents of children with ASD often report that their children are "overly honest," in that they immediately say exactly what they are thinking, regardless of what the social consequences may be. For example, if a child with ASD receives a gift from a friend and does not like it, he or she may say something overly literal, such as, "I don't want this," rather than a more socially appropriate response to receiving a gift, such as, "Thanks!" Similarly, a child with ASD may share his or her opinion of someone else when it is not necessary and certainly not socially successful to do so. For example, if a peer comes to school with a new hairstyle, the child with ASD might say something like, "You got a haircut. I think it looks stupid," when a more socially effective response would be either to not comment on the new hairstyle or to tell a "white lie," such as, "Cool new haircut."

In the cases of both understanding the deceptive language of others and in engaging in deception, a relation of distinction exists between observed reality (or inferred likelihood) and what is said. Successful deception likely involves an effective behavioral repertoire of relating events in terms of distinction. This situation is similar to sarcasm, as described earlier, in that what is said is not what is really meant. The major difference is that, in sarcasm, what is said is the exact *opposite* of what is meant (thereby necessitating relating in terms of opposition), whereas in deception, what is said is merely *different* from what is meant, not necessarily the opposite (thereby necessitating relating in terms of distinction or difference). Future research should attempt to teach children with ASD to tell "white lies" by presenting multiple situations in which something other than the truth should be said for social reasons, perhaps simply to be polite. Again, it seems likely that providing rules and training across multiple exemplars, settings, and people could be successful in establishing the ability to engage in socially appropriate deception.

Self-Management

Self-management involves the application of techniques such as self-monitoring, self-evaluation, and self-reinforcement to modify one's own behavior (Malott 1989). It is a treatment option that promotes independence and carries the potential to result in widespread behavioral change. The clear advantage to teaching individuals with ASD to use self-management is that it may reduce the need for treatment providers to be present around the clock in every setting (Koegel and Koegel 1990), making it ideal for children integrated into educational and community settings.

Several studies have successfully trained children with ASD to self-monitor various behaviors and have demonstrated maintenance in the absence of a treatment provider. Koegel and Koegel (1990) taught children with ASD to self-monitor their stereotypical behavior and implement a differential reinforcement of other behavior (DRO) procedure across settings (including the community). The treatment provider was faded out and the reinforcement scheduled thinned, resulting in maintenance of reduced stereotypy and use of self-monitoring in the absence of a treatment provider over time. Koegel et al.

(1992) improved social responsivity in children with ASD across home, school, and community settings by teaching participants to self-monitor appropriate responses to the social initiations of others on a wrist golf counter. As in the earlier study by Koegel and colleagues, using a fading procedure and reinforcement schedule thinning, results were maintained in the absence of a treatment provider. Interestingly, the authors also concomitantly found that untargeted disruptive behavior was much less than before in previous problematic community settings. Stahmer and Schreibman (1992) taught children with ASD to self-monitor appropriate play using a chronograph alarm wristwatch. The treatment provider was faded out and the reinforcement scheduled thinned, resulting in maintenance of appropriate play in the absence of the self-management materials and treatment provider. Generalization across settings and toys was also observed and a collateral decrease in untargeted stereotypical behaviors was observed. Pierce and Schreibman (1994) taught self-management of daily living skills to children with ASD using picture books. The treatment provider was faded out completely, and the picture book was faded out for some but not all tasks. Generalization across settings, maintenance at a 2-month follow-up, and a concomitant decrease in stereotypical behavior was also observed.

Parents of children with disabilities spend a great deal of time tending to their children's needs and share the common concern of their offspring's lack of independence and ensuing burden of care (Koegel et al. 1992), implicating a strong need for effective strategies for promoting autonomy in this population. Taken together, these studies provide evidence that use of straightforward operant techniques such as prompting, prompt fading, stimulus fading, reinforcement schedule thinning, and the like are capable of teaching children with ASD to engage in self-management independently. Future research should investigate the possibility of extending this line of research to the level of teaching a generalized operant repertoire of self-management (i.e., teaching children to identify areas to self-manage and to establish their own self-management programs for achieving goals).

Rule-Governed Behavior

The term "rule-governed behavior" refers to the ability of typically developing adult humans to behave with respect to things that have not yet happened, in such a way that life is safer and more efficient. The defining feature of rule-governed behavior is that it is a behavior that occurs *as though* one has contacted a contingency, even though one has never done so. For example, one never has to actually contact the consequences of drinking bleach in order to avoid drinking bleach, rather one may merely hear the rule, "Don't drink bleach or you will die." It is hard to overestimate the importance of rule-governed behavior to human society. Skinner (1969) points out virtually all vestiges of society would be impossible if every individual human had to come in contact with the consequences of their own behavior and knowledge for effective action could not be passed down throughout the generations through language. Most of science is rule-governed behavior. Just imagine, if engineers could not understand descriptions of scientific rules derived from previous research, every engineer would have to discover Newton's laws of motion from their own fumbling. Indeed, no laws of any sort, virtually no education, no ethics, currency, or any other foundational institution of human society would be possible if each individual human had to learn all of the consequences of their behavior through direct contact. In short, rule-governed behavior is how cognitive and linguistic knowledge is passed on from one human to another and is therefore present in virtually everything typically developing adult humans do on a daily basis.

Despite the clear importance of rule-governed behavior, surprisingly little research has addressed it and less still has been done on behavioral interventions for establishing it in individuals who do not already display it. Tarbox et al. (2011) conducted the first and only study, to our knowledge, that attempted to establish a rudimentary form of rule-governed behavior in individuals with ASD who did not already display it. In two experiments, children with ASD were trained to respond correctly to instructions that described an antecedent and a response (e.g., "If this is a carrot, then clap your hands"). After training on a large variety of exemplars, all children displayed correct responding to antecedents and responses that were never included in training. This outcome is a far cry from what most consider a full repertoire of rule-governed behavior displayed by most typically developing adults. For example, rule-governed behavior is distinguished by the fact that the consequence may be long delayed or nonexistent (e.g., going to hell) or there may be a long delay between hearing the rule and the opportunity to respond (e.g., hearing a rule about what you should do tomorrow). Nevertheless, learning to understand and respond to novel, untrained rules containing basic contingency statements is likely the first step in developing a larger repertoire of rule-governed behavior and there is no reason to believe that later steps cannot be taught as well. Indeed, it seems more likely that establishing the generalized repertoire of conditional relating is the most difficult part, while expanding it to be more complex and more elaborate may simply be a matter of time and degree. Much more research is therefore needed on establishing rule-governed behavior in individuals with ASD.

Visualizing

Visualizing is a particularly abstract and mysterious form of covert behavior. In essence, it involves "seeing" something that is not physically present (Skinner 1974). No previous research of which we are aware has attempted to teach visualizing to children with ASD but a recent pair of studies has done so with typically developing preschool children (Kisamore et al. 2011; Sautter et al. 2011), and the implications for children with ASD are promising. In both studies, typically developing preschool children were tested on their ability to name stimuli that are members of particular categories (e.g., "Tell me some animals"). During baseline, the performance of all participants was low. During intervention, children were taught to imagine cues for subclassifications of the stimuli and then taught to name the stimuli that belong to the subclassifications. For example, when asked to name some animals, children were taught to imagine a farm and name the animals in it, then an ocean and the animals in it, and then a zoo and the animals in it. Children were also prompted to use the imagining strategy and were given rules describing the use of it. This package intervention generally improved accuracy on the categorization task across most participants. Future research should attempt to apply similar strategies for teaching visualization as a problem-solving strategy to children with ASD, as well as assessing to what extent such problem-solving repertoires can generalize to untrained stimuli and problems.

Derived Symmetry

A number of studies using MET to establish generalized-derived symmetry repertoires in children have been published. Much of this research is on various forms of verbal behavior. Although addressing cognition is not the stated purpose of this line of research, it certainly demonstrates the effectiveness of behavioral intervention for remediating deficits in abilities that traditional linguists relegate to cognitive constructs, such as the "language acquisition device."

For example, Greer et al. (2005) demonstrated listener to speaker transformation of function (emergence of untaught impure and pure tacts following training in matching) using MET in children with mild disabilities. In this study, participants were first taught matching (e.g., "Match Labrador") for a set of stimuli, resulting in failed emergence of impure and pure tacts. Then, participants were taught listener (matching and "point to") and speaker (impure and pure tacts) repertoires for a second set of stimuli, resulting in an emergence of speaker responses in the first set of stimuli. Finally, matching responses taught alone with a third set of stimuli resulted in the emergence of the speaker component. In a follow-up study, Fiorile and Greer (2007) sought to determine if MET with sets of stimuli would result in speaker to listener transformation of stimulus function following tact training alone in children with ASD. Results demonstrated that naming did not occur until MET was used to train both speaker and listener repertoires. Following this, participants were able to acquire naming in new sets of stimuli following tact training alone. In another study, Pérez-González et al. (2007) demonstrated emergence of intraverbal antonyms (e.g., participants saying "hot" in response to "name the opposite of cold," and vice versa) in children with pervasive developmental disorder (PDD) following use of MET wherein reversed stimulus-response functions were directly trained with pairs of intraverbals.

Future Research

The research described above provides an encouraging start to research into behavioral intervention for teaching cognitive skills to children with ASD. However, there is still much work to be done. In what follows, we discuss potential future directions for behavioral research into additional areas of cognition.

Perspective Taking

As described earlier, little behavioral research has been done on teaching children with ASD perspective-taking skills. In a chapter dedicated to the topic, McHugh et al. (2009) extrapolate a logical process, taken from the RFT literature, by which perspective taking should be trainable in individuals with ASD. The chapter focuses on training flexible, arbitrarily applicable relational responding in terms of three relations: I/you, here/there, and now/then. The I/you relation is perhaps the most fundamental to perspective taking and involves responding to the relation between oneself and someone else. Furthermore, a well-developed I/you relational repertoire should allow one to alternate between responding to oneself versus someone else as illustrated in the following example: "I have a cookie and it makes me happy. How would Jimmy feel if he had a cookie?" and the reverse, "Jimmy is happy because he has a cookie. How would I feel if I had a cookie?" Responding in terms of here/there relations is relevant to perspective taking because one is always here, that is, one is always in one's own skin. Others are never here (in one's own skin) and are always "there," that is, somewhere other than one's own skin. Understanding and using now/then relations is also relevant to perspective taking because combined with either I or you, one is required to respond in relation to either oneself (I) or someone else (you) in accordance with either today (now) or yesterday and beyond (then). For example, one would be able to respond to the following correctly, "Yesterday, I was playing at the park; today I am watching a movie. What was I doing then? What am I doing now?" regardless of whether I or you is placed into the scenario. The chapter lays out a logical progression for how these repertoires might be trained and readers are encouraged to reference it when creating any programs of research or practice in training perspective-taking skills.

Understanding others' intentions One of the many private events of others that one must be sensitive to in order to be socially successful is intentions. Parents of children with ASD often report that their children have difficulty judging whether the actions of others are intentional. For example, a child walking down a crowded hallway in school is likely to have another child bump into him or her. If this happens unintentionally, the socially successful response is of course to make nothing of it. However, if the other child intentionally bumped into one, as in a case of bullying, an appropriate response might be entirely different. Other similar situations include another person accidentally knocking over a toy, dropping food, or stepping on one's foot. For the most part, typically developing children acquire the skill to discriminate between intentional and unintentional acts, but this discrimination may not develop in some children with ASD if it is not specifically taught. It seems plausible that subtle cues in the environment are present that allow one to make such discriminations and future research should attempt to use MET to teach children to make these discriminations.

Identifying others' knowledge Another skill important for promoting successful social interaction is the ability to identify whether another person has knowledge of particular things and events. Typically developing children begin to do this at around the age of three and are able to identify why others hold certain knowledge around four or five, for example, they can identify that someone knows about something because they saw it (O'Neill et al. 1992).

Being able to identify whether another person knows about something is crucial to everyday social functioning. When having a conversation with another person, for example, it is necessary to provide just the right amount of detail and background information needed by the listener. In telling a story about something that occurred yesterday, one would not spend time recapturing events that the listener already knows about (whether having already heard about it or having been present to witness it). Or, in having a conversation with a person about a specialized topic, one would consider whether the person has had any previous exposure or experience with the topic. If the person has had advanced exposure, one would not spend time providing explanations and defining the topic; however, if the person has had little or no experience, one would either choose not to converse on the topic or would provide sufficient background detail to get the listener up to speed.

Oftentimes, one will also refer to another's knowledge when attributing fault or blame. For example, a person will not be held accountable for their mistake, if they do not know any better. Thus, in deciding whether to place blame or allow forgiveness for another's actions, one will often refer to how much knowledge the person possessed in the given situation. In using deception, one will also refer to another's knowledge and will go to great lengths to ensure that others do not gain knowledge about the information being withheld, for example, when keeping secrets and surprises, or when telling a joke or bluffing. And, in some cases, one will lie in an attempt to influence what others know.

The ability to identify what another person knows involves understanding that other people only know about things and events they have experienced either directly or indirectly. A generalized operant repertoire of identifying whether or not others hold certain knowledge and how or why they hold that knowledge should be teachable using MET. Presumably, this could be taught by first teaching children with ASD that another person knows something if they have experienced it (i.e., seen it, heard about, been told about, read about it, smelled it, tasted it, felt it, etc.), and then presenting many different scenarios of observing another person either experience something or not experience it, and then asking whether or not that person holds knowledge about the event and why they do or do not hold that knowledge. With enough exemplars trained across each experiential category, a generalized operant repertoire should emerge resulting in being able to identify whether another person knows something in novel situations with novel stimuli, people, and experiential categories presented.

Problem Solving and Rule Deriving

Problem solving is an area of cognition in which individuals with ASD have documented deficits and yet few or no previous studies have attempted to treat these deficits. If problem solving consists of a variety of generalized relational operants, it should be teachable. Skinner defined problem solving as a situation in which reinforcement would be forthcoming if a particular behavior was performed but the person has never performed the behavior under these circumstances (i.e., he/she does not "know" what to do; 1957; 1969). Problem solving is a name for the set of behaviors the individual engages in that results in the terminal behavior becoming clear. In other words, it is the complex array of behaviors in which one engages to "figure out" what final behavior will solve the problem. There are likely many such complex behaviors, but one in particular stands out: The ability to derive cause and effect statements about the problem with which one is confronted. When successfully solving a problem, one seems to be engaging in self-talk of this sort: “If I do X, then Y will happen, and then I’ll be able to do Z, which will solve the problem.”

Deriving cause and effect statements about contingencies between antecedents, behaviors, and consequences is referred to as rule deriving in behavioral literature. No previous studies, of which we are aware, have established this ability in someone who did not previously display it. In the 2011 study by Tarbox et al. described above, children with ASD were taught to understand novel rules. However, these rule statements were made in a clear and salient manner, as the participants were not expected to “figure them out” themselves. It seems logical that understanding rule statements would be a prerequisite to deriving them, thus teaching children with ASD to derive their own rules is the next logical step in this line of research. It should not be unreasonably difficult to do. By definition, the individual already has a generalized repertoire of relating stimuli and behaviors in terms of conditional or causal relations, however, only “receptively,” that is, by responding to statements of those relations, not by creating those statements. It seems logical that the “expressive” repertoire should be readily teachable through MET. Such training would likely involve exposure to a large variety of problems, wherein a teacher directly prompts the child to make statements about antecedents, behaviors, and consequences, and then prompts him or her to behave in accordance with those statements, thereby contacting the naturally reinforcing consequences for deriving and following the rule. For example, a child might be given a favorite toy that is not working. The child might be prompted to look at the batteries and buttons and/or to look for missing pieces, and so on. The child would also be prompted to identify the problem, describe possible solutions to the problem, and what would happen if he or she implemented one or more of them (e.g., “I could put batteries in the game. If I do this, it will work and I can play with it”), and actually fix it. Training would presumably be required across a large variety of exemplars and the only meaningful test would be to evaluate whether rule deriving (and therefore successful problem solving) occurs with novel problems, containing novel stimuli, and untrained solutions. Successful performance under such tests would be evidence for the establishment of a generalized problem-solving cognitive ability. Later, if appropriate, one could likely teach the child to engage in the rule-deriving self-talk at the covert level, making the skill more discrete.

Flexibility

An insistence on sameness is a defining feature of ASD. This general pattern of restricted interests and repetitive behavior looks different for each individual, and can be as straightforward as engaging in the same motor behaviors repeatedly (e.g., hand flapping), repetitive social behavior (e.g., talking about only one topic of conversation), or can be more “cognitive” in nature, such as having difficulty with thinking of things in new ways or solving new problems that require one to adjust to new variables. Much has been said about more straightforward forms of stereotypy, and a large treatment literature exists (Rapp and Vollmer 2005). Here, we consider flexibility and inflexibility as they pertain to cognition.

An intense interest in sameness and repetition can be adaptive under certain circumstances, such as maintaining focus on creating a particular computer program that requires countless hours of staring at a computer code. However, in many circumstances, insistence on sameness can create difficulty, for example, when adapting to a new job, adjusting to a new classroom or teacher, being confronted with new routines, or being introduced to entirely new educational lessons in school. It is not clear why many individuals gravitate toward repetition and sameness but one potential explanation is that novelty, per se, is aversive. That is, the physical properties of a stimulus may be less important than the fact that those properties are different from the properties of previously contacted stimuli. In some cases, even familiar stimuli may be aversive when they merely appear in unfamiliar contexts or routines. In this case, the very sequence, order, or routine itself, seems to be the source of aversive stimulation. Of course, all organisms avoid aversive stimulation, so it is not surprising that individuals with ASD would attempt to avoid such situations if they are indeed aversive.

Although we have no idea why novelty would become a source of aversive stimulation, behavioral principles and procedures thankfully provide readily available options for how to make novelty less aversive. The principles of habituation and conditioned reinforcement should likely be useful. Decades of research on habituation have shown that merely through repeated presentation, the potency of a stimulus decreases over time (Rankin et al. 2009). If novelty, per se, is the source of aversive stimulation, then repeated presentation of novel stimuli should reduce its aversiveness. Of course, presentation of a variety of dissimilar exemplars should be necessary to ensure one is not merely producing habituation to particular stimuli, but rather novelty, per se. The habituation procedure just described might be enhanced by not merely presenting novel stimuli but by also pairing them with known reinforcers. This should have the combined effect of repeated exposure to novelty but also potentially conditioning novelty, per se, to be a source of conditioned reinforcement. The effectiveness of this procedure could be easily tested by presenting additional novel stimuli which were never presented during training and assessing the extent to which the individual attempts to avoid them. Such a procedure should be relatively straightforward, but little research of which we are aware has attempted it.

If novelty, itself, were made to be less aversive or perhaps even a source of conditioned positive reinforcement, it would be interesting to assess how broadly this effect can be generalized. For example, an individual may be inflexible about the colors of food that he eats, the route that he must be driven to school, the order in which he dresses, where he sits when he completes homework, the arrangement of who sits in which seat at the table, the manner with which he attempts to solve novel problems, the sort of music he will tolerate, and many other situations. If the procedure described above worked, it would be interesting to assess the extent to which intervening with exemplars of some types (e.g., food and homework) would produce a generalized ability to tolerate novelty with completely different types of stimuli (driving directions and seating arrangements). In behavioral perspective, the greater the extent to which generalization is observed, the greater one can be said to have actually improved “cognitive flexibility,” as opposed to merely adaptation to particular stimuli.

Conclusion

Despite the promising utility of treating cognition as generalized operant behavior, the approach is not without its limitations. The first and most obvious limitation is that the biological and physiological limitations on cognition will presumably never be overcome, regardless of the effectiveness of behavioral habilitation. We assume that each organism inherits physiological limits within which their behavior can be shaped. For example, humans will never learn to fly unaided by equipment, no matter how well they learn to flap their arms. In the realm of cognition, each organism likely comes equipped with a range of potential development in each particular area. Not every human is going to be capable of reasoning at the level of Albert Einstein, no matter how optimal their learning environment. Similarly, every child with ASD will struggle with different limits to their cognitive learning. However, the same can be said of anyone in any area of human endeavor (e.g., athletics, academics, etc.), and this is by no means a reason to abandon efforts at maximizing progress. Furthermore, there is currently no way to even grossly measure the capacity for skill development in children with ASD, so every child deserves a chance at maximizing their development in all areas, including cognition.

The existing research on behavioral intervention for improving cognitive skills in children with autism is still quite preliminary. As described above, promising results have been obtained across a variety of skill areas including perspective taking, sarcasm, metaphors, derived symmetry, self-management, and working memory. However, the full realm of cognitive skills in which humans engage is massive and current research has only scratched the surface. We have noted that the radical behavioral and RFT perspectives are useful foundations for research and practice in teaching cognitive skills because they point to variables which are actually amenable to manipulation: Those found in the child's learning environment. We hope that this burgeoning area of research will continue to be expanded and the full potential of MET and other behavioral procedures will be brought to bear on teaching cognitive skills to children with autism.

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19

Teaching Independent Living Skills to Children with ASD

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Keywords

Self-care · Activities of daily living · Independent living

> Sam, a 26 –year- old man with autism, lives at home with his parents. Despite being enrolled in special education from the age of three until he was 21 and having an IQ of 65, he is reliant on his parents for all of his self-care needs. His parents prepare all of his meals, shower him, remind him when to use the bathroom, and assist him with dressing and all areas of personal hygiene. For Sam, reliance on his parents has significantly limited his opportunities to participate and engage in community-based living, work, and recreation activities. As a result, Sam spends most days at home with his aging parents, isolated from peers and engaged in unproductive activities.

Sam's functioning and outcome may seem alarming, particularly in the current zeitgeist advocating ever earlier and ever more intensive intervention for children with autism. But research indicates that Sam's outcome may not be so unusual. Howlin et al. (2004) for example, found that of 68 adults with autism, who had IQs above 50 in childhood, over 50 % had outcomes described as poor or very poor; only eight were independently employed, and only three lived outside of their parent's home with minimal support. Similarly, Eaves and Ho (2008) found that of 48 young adults, at age 24, only four lived independently, only one worked competitively, and almost half of the group had never been engaged in any work activities. While early intensive intervention based on applied behavior analysis no doubt improves outcomes for individuals with autism (Peters-Scheffer et al. 2011), many will remain dependent on others to initiate, sustain and to complete independent living tasks, even after the skills have been acquired (Hume et al. 2009). If we are to change this trajectory for adults with autism, curriculum design for very young children with autism must be visionary; taking into account the skills necessary for independent functioning, and incorporating research-based strategies that reduce reliance on caregiver prompts (Maurice and Taylor 2004).

This chapter will: (a) define independent living skills and the challenges related to independence in children with autism, (b) review the research on teaching independent living skills, (c) suggest instructional strategies that may increase overall independent functioning in individuals with autism, and (d) outline some essential skills to target with very young children with autism.

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Why Address Independent Living Skills with *Young* Children with Autism?

Independent living skills are any skills necessary to engage successfully and productively in a variety of activities without caregiver prompts. Most consider these skills to be in the area of self-care (e.g., toileting), daily living (e.g., preparing a meal), and employment (e.g., completing a work assignment). It goes without saying that independence in these areas improves quality of life not only for the individual with autism but also for his or her family. If caregivers are relieved of the burden of the day-to-day care of their adult child with autism, they will experience less stress and can participate with their loved one with autism in other more meaningful activities. Autonomy in these areas will also increase opportunities to participate in mainstream and community-based learning experiences, reduce the need for long-term care and the associated costs to family and society, facilitate personal privacy and safety, and increase overall self-sufficiency.

While most independent living skills become increasingly relevant as children get older, early curriculum objectives can set the stage for more complex repertoires of independent responding. Take for example a young child with autism who is unable to start and finish a puzzle. Teaching her to complete such activities without an adult present in her environment will likely make teaching her to complete self-care tasks without caregiver prompts in the future a more efficient process. In other words, targeting tasks and skills that lead to the initiation of and independent performance of a variety of tasks in early childhood will likely impact performance in independent living as the child ages. Thus, just as an early learning curriculum must focus on the initiation of language and the reciprocation of social skills, so should there be an emphasis on identifying tasks that will impact independent living for the child with autism.

Challenges with Independence

Children with autism present with a complex array of skill deficits and learning challenges. These challenges can impede the acquisition, generalization, and maintenance of independent living skills, and have implications for designing effective intervention programs. Children with autism may, for example, over attend to irrelevant features of a learning context, often referred to as “stimulus over-selectivity,” and as a result fail to initiate or respond in other contexts where specific skills are essential (Ploog 2010). Take for example, a child who learned to independently complete all the steps to wash his hands at school, but when getting a paper towel for drying his hands, over attends to a written logo on the paper towel dispenser. As a result, when he is in a different bathroom he is unable to locate the paper towel dispenser because it does not have the same logo. Here, the failure to recognize all paper towel dispensers as the same prevents the child from completing all the necessary steps to wash his hands independently in novel settings.

Stimulus overselectivity can also lead to dependence on the prompts provided by caregivers during teaching interactions. A child who has been prompted by his teacher to pick up the soap during a hand-washing routine by the teacher pointing to the soap, may over attend to this cue and as a result wait for her cue before getting the soap in the future. That is, rather than each step of hand washing serving as a cue for the next response in the chain, the child waits for his teacher to point to each item before initiating each response. In this example, the failure of the instructor to fade his/her cue is detrimental to the learning process, and as a result the child fails to perform the task independently.

Deficits in responding to social reinforcers and punishers may also impede the acquisition and maintenance of independent living skills. Children with autism often lack an awareness of the subtle social responses of others, and the effect that their own behavior has on others (Baron-Cohen et al. 1985). A teenager with autism, for example, may not notice food on his face after a meal. Most typically developing teenagers would, upon seeing the food on their face in the mirror in the bathroom, quickly wipe it away—most likely to avoid social disapproval from peers. A teenager with autism on the other hand may not readily wipe the food away because social disapproval may not be experienced as unpleasant. As a result, the teenager with autism fails to engage in a response to avoid such disapproval. Similarly, many early independent living skills are responded to by the social praise of parents, such as a mother saying to her child, “I’m so proud of you when you clean up your toys all by yourself.” If social praise does not function as a reinforcer, the child may not acquire these responses. For a child with autism who does not discriminate or identify the social reaction of others, perceive social disapproval as punishing, or experience social praise as a reinforcer, he may lack the motivation to engage in relevant independent living skills and only do so when prompted by caregivers.

The overuse of contrived schedules of reinforcement may also inhibit the maintenance independent living skills if instructors use schedules of reinforcement that are not comparable to nonteaching environments. For example, if during instruction, the teacher uses a very dense schedule of food reinforcement to shape a learners’ completion of a dressing routine, and does not thin that schedule of reinforcement before discontinuing intervention, the skill may not maintain over time or be displayed in other environments where lean schedules of reinforcement are the norm. As a result, the child may not perform the skill independently with his mother, who sporadically provides social praise for completing the dressing routine.

Additionally, most independent living skills encompass a number of component responses that are linked together in a chain of responses. The skill of making a bed for example, comprised several responses (e.g., pulling the top sheet up to the pillows, pulling the blanket up, folding the top of the blanket down, and so on). Children with autism are therefore required to perform many responses in a row before a reinforcer is provided. Maintaining endurance and performing all responses within the chain may be challenging especially if the majority of instruction for the child with autism has involved performing single responses (e.g., tacting a photo) before a reinforcer is delivered.

Independence can also be affected when a child is not fluent in performing each component response within a behavioral chain (Johnson and Layng 1996; Twarek et al. 2010). For example, if a child is unable to snap his pants after using the restroom, he will always require assistance completing the entire response chain required to use the restroom. Unless each component response in the behavioral chain can be performed with speed and accuracy, the entire response chain may not be completed and assistance at some point in the chain will be required.

Independence with self-care, self-help, or personal hygiene skills also requires proficient gross and fine motor skills, often found to be impaired in children with autism (Provost et al. 2007). Getting dressed, for example, requires fine motor responses such as grasping socks, placing socks over the toes, and pulling the socks over the foot and heel. Thus, deficits in fine motor skills could interfere with the learning of and independent performance of a variety of daily living skills by children with autism (Jasmin et al. 2009). As such, teachers should likely give consideration to teaching fine motor skills which will be essential for independent living tasks.

The challenges outlined above highlight the need for careful planning and implementation of instructional strategies for ensuring success with independent living skills. We will outline how these challenges can be addressed in the Instructional Strategies section. Let us first focus on empirical investigations of such strategies as they relate to teaching independent living skills.

What Research Tells Us

Conducting a search of the literature using the terms, “self-help,” “daily-living,” “life skills,” and “independent living” skills yields a number of studies evaluating a variety of techniques for improving toileting, dressing, bathing, hygiene, housekeeping, and meal preparation repertoires of adults and adolescents with autism (Matson et al. 2012). However, despite the many book chapters and “how to” guides for professionals and parents, published empirical studies evaluating effective strategies for teaching these repertoires to *very young* children with autism are scarce. This may be because some of the specific skills commonly associated with activities of daily living such as applying deodorant, shaving, doing laundry, and using a knife, are not developmentally appropriate targets for younger learners. More commonly, research with early intervention populations target toileting and feeding (Wallace and Fryling 2011). This discrepancy in research requires clinicians working with young populations to extrapolate strategies from the literature demonstrated to be effective with older learners and apply them to building these repertoires in younger learners.

Toileting and Feeding Research

Independent living requires individuals to be independent with toileting. Reaching a completely independent level of toileting however, is often challenging for learners with autism and may take years to acquire (Flynn and Healy 2012). There are two possible reasons for this. First, appropriate toileting requires the acquisition of many response classes that often have to be taught separately. For example, discriminating the stimuli associated with a full bladder, communicating the need to use the toilet, dressing and undressing, using toilet paper, flushing the toilet, and elimination responses are all individual repertoires necessary for independent toileting.

Second, it has been argued that both the verbal and cognitive ability of the learner impacts the intensity of the training and overall length of time required to achieve independent toileting. Specifically, lower cognitive and verbal levels are associated with longer acquisition periods (i.e., up to 3 years) and an increased rate of regression following training (Dalrymple and Ruble 1992). Considering children with autism under the age of five are likely to have lower verbal and cognitive skills than their peers (Hudry et al. 2010), it is no surprise that the majority of interventions that have reported success with toilet training have been conducted with children with autism over the age of five (Flynn and Healy 2012).

The majority of toileting interventions reported in the literature with young children are modifications to the original intensive rapid toilet training method developed by Azrin and Foxx in 1971. Individual techniques for training toileting skills are often combined and used as a training package and include graduated guidance, positive reinforcement, scheduled sitting, punishment, hydration, elimination schedules, and priming or video modeling (see Flynn and Healy 2012; Kroeger et al. 2009 for reviews).

Although toileting is considered necessary for independent living, feeding is necessary to sustain life. Some researchers have argued that the atypical eating habits of children with autism are related to the core deficits of autism such as restricted interests, behavioral rigidity, and/or perseveration (Ledford and Gast 2006). Feeding issues commonly addressed in the literature are food selectivity, food refusal, lack of independent feeding skills, and problem behavior during feeding when presented with non-preferred foods (see Sharp et al. 2010, for a comprehensive review).

Behavioral interventions have proven successful as a solution for feeding challenges of young children. Although feeding problems are common among children with autism, the majority of research regarding effective treatments has focused on other pediatric populations without autism and with a variety of medical illnesses. Empirical evaluations of effective feeding treatments for autism have included differential reinforcement, escape extinction, stimulus shaping, stimulus fading, and pairing (Ahearn et al. 1996; Anderson and McMillan 2001; Valdimarsdottir et al. 2010). Thus, with respect to both toileting and feeding, the most commonly targeted independent living skills in young children with autism, multicomponent treatment packages are widely used and accepted.

Research on Other Self-Care Skills

Although scarce, procedures for increasing independence with daily living skills have been experimentally evaluated and reported with children with autism as young as age three (Rosenberg et al. 2010). Common teaching strategies outlined in the research include video modeling, photo activity schedules, chaining procedures, self-operated auditory prompts, and general prompting and reinforcement packages. For example, Shipley-Benamon et al. (2002), found that viewing a video of a model performing a task prior to an opportunity to engage in the task was effective for teaching 5-year-old children with autism to perform response chains such as caring for a pet, setting the table, and preparing orange juice. Rosenberg et al. (2010) evaluated the effects of commercially developed videotapes on teaching hand washing to 3–5 -year-olds with autism and found that only one of the three participants acquired the responses using the models portrayed on the tapes, while the other two participants required more individualized models to fully acquire the response chains.

Pierce and Shreibman (1994) found the use of pictorial prompts within activity schedules to be effective at facilitating independence with self-care tasks such as getting dressed, setting the table, and making lunch for children with autism 6–9 years of age. Recently, Mays and Heflin (2011) found the use of self-operated auditory prompts (verbal prompts recorded on an audio recording device) effective for increasing independence with hand washing and toothbrushing response chains by 6–12-year-old children with autism.

Other studies have investigated various prompting and reinforcement procedures. For example, Matson et al. (1990) found that total task presentation and a training package which included modeling, verbal instructions, prompting, and edible and social reinforcers was effective to increase various self-care tasks such as tying shoes, brushing teeth and hair, getting dressed, and eating and drinking in 4–11 -year-olds with autism. Sewell et al. (1998) used simultaneous prompting, physical guidance, and the natural reinforcement of going outside to teach preschoolers with autism to put on their coats.

The results of these studies are promising in that they can inform clinicians working with younger populations about strategies used to target independent living skills. The extent to which these strategies are effective with *very* young learners such as toddlers with autism, however, requires more experimental evaluations. The following section provides a discussion of considerations when developing interventions for teaching independent living skills to young children with autism.

Instructional Strategies

Transferring Stimulus Control Using Prompt Fading

At the foundation of any strategy used to increase independence is the concept of stimulus control. Stimulus control involves performing a response in the presence of specific stimuli, and not performing the response when those stimuli are not present. When preparing to teach any independent living skill to a child with autism, a teacher should ask “Under what conditions should this response occur?” or, “What in the environment should cue this response?” The answer to these questions should lead to the identification of stimuli that should and should not be present when teaching the target response(s), and help to identify the stimuli that will eventually come to “control” the response(s) in the natural environment once teaching has ended. Identifying the target controlling stimulus/stimuli from the outset will help facilitate the eventual performance of that skill without prompts. When independence is demonstrated in the presence of the naturally occurring stimulus, appropriate stimulus control over responding has been established. For example, hand washing should be cued by a child noticing that his hands are dirty, not by his teacher’s directive. In this example, his dirty hands are the naturally occurring stimuli that should control responding if truly independent responding is desired.

Facilitating stimulus control by target stimuli involves reinforcing the response in the presence of the target stimuli and withholding reinforcement if the response occurs in the presence of any other stimuli. Essentially the trainer is teaching the learner to discriminate when and when not to exhibit a particular response (Green 2001). The stimulus that is present when a response is reinforced comes to control the response and is referred to as a discriminative stimulus. For example, when teaching a child to wash her hands, the teacher would point out the child's dirty hands, prompt the behavior (hand washing) and provide reinforcement following hand washing. Over time, this consistent pairing of the stimulus (dirty hands), and the response, hand washing, followed by reinforcement, should result in dirty hands controlling the response of hand washing, provided that the point prompt is effectively faded out.

Typically, during initial instruction, prompts control responding. For example, a child may only unzip his coat if his teacher's hand is placed on his hand to guide him to unzip the zipper. The ultimate goal with any prompting, however, is to shift stimulus control from prompts to the natural cues in the environment (in this case, entering school and standing in front of his locker). To transfer stimulus control, prompts are faded by gradually using less and less assistance and providing reinforcers contingent upon responses requiring less assistance. For example, the teacher may guide the child's hand by placing her entire hand over his hand to unzip his coat. Then she would gradually use less assistance by holding the child's wrist, then gradually shadowing his hand and then removing her hand altogether so that the child unzips his coat independently when he is standing in front of his locker. For all of the interventions outlined below, efforts should be made to identify a controlling prompt (i.e., one that evokes behavior) and the natural cue in the environment, and develop ways to systematically fade the controlling prompts until the child is responding to a natural cue in the environment independently.

Reinforcement

It goes without saying that attempts at establishing stimulus control over skills associated with independent living will be unsuccessful without the effective use of reinforcement. Generally speaking, it is common that continuous schedules of reinforcement facilitate acquisition of new responses and intermittent schedules of reinforcement facilitate maintenance of responding over time. For example, when first teaching a child to tie his shoes, every instance of shoe tying would be followed by reinforcement, and then every other instance, and every third, and so on until reinforcement is gradually thinned to match the schedule of reinforcement that occurs in the natural environment (e.g., mom occasionally providing praise for shoe tying). Because the schedule of naturally occurring reinforcers rarely match the schedule of reinforcers present in the training environment, clinicians should make a concerted effort in training to thin schedules of reinforcement systematically within their training sessions so that skills will be more likely to maintain once training has ended.

The use of reinforcement requires the occurrence of a response. However, if we simply wait for the desired target response to occur, few children would learn to dress themselves, use a fork, or wash their hands. Shaping is a procedure that is useful when the occurrence of the final target behavior is very complex and is either occurring at very low rates or not at all. Technically defined, shaping involves gradually modifying some property of responding by differentially reinforcing successive approximations to the target response (Cooper et al. 2007). Let us take the case of a child who has learned the response chain of hand washing, but only briefly holds his hands under the water to rinse away the soap. It may be determined that 10 s is an appropriate duration for rinsing. In this example, the property of responding that requires modification is duration of rinsing. To shape the response, reinforcers are provided at first for holding his hands under the water for 3 s. Reinforcement is then only provided for rinsing for 5 s. The criterion for reinforcement is gradually increased contingent on success at the last criterion until the child is rinsing his hands for the target duration of 10 s.

Identifying potent reinforcers to shape behavior is essential for any intervention plan. Preference assessments can be conducted to identify preferred items that could be used as potential reinforcers during teaching interactions (e.g., Fisher et al. (1992)). Ideally, the stimuli identified as potential reinforcers should be able to be provided efficiently when teaching a child to complete a long response chain. For example, access to a preferred video on an iPad may disrupt the chain of shoe tying if this activity is provided as a reinforcer for completing each step associated with the task. Preferred edibles (e.g., small portions of a preferred food items) provided directly to the child, on the other hand, may be more efficient in shaping responses demonstrated in a task consisting of multiple responses in a chain.

The presentation of preferred stimuli as reinforcers has implications for conditioning social praise as a reinforcer for young children with autism. As described earlier, many young children with autism may not appreciate social praise and interaction as reinforcers. For this reason, praise statements are often presented along with preferred items so that social praise eventually comes to function as a reinforcer. For example, a caregiver teaching a child with autism to put on his shoes would provide a praise statement (e.g., “Good boy! You put your shoes on!”) along with a small treat (e.g., an edible) or access to a preferred toy (e.g., a toy train). Eventually, the praise statement should begin to function as a reinforcer. Since the reinforcers available in the “natural” environment will most likely be praise, this pairing is essential to ensure maintenance of performance in the real world once training has ended.

Motivating Operations

Teachers can increase the motivation of learners to perform during teaching interactions by capturing or manipulating motivating operations. A motivating operation (MO) is an environmental variable that alters the reinforcing effectiveness of a stimulus while also altering the current frequency of behaviors that have been reinforced by that stimulus in the past (Laraway et al. 2003; Michael 1993). The reinforcing effectiveness and the current frequency of behaviors can either be increased or decreased, depending on the environmental variable that is presented. For example, if we are attempting to teach a child to request water when he or she feels thirsty, allowing the child to consume salty snacks creates a motivating operation for water: The water itself will function as a potent reinforcer for the behavior of requesting water, and requesting is likely to increase in the presence of stimuli associated with access to water (e.g., seeing a water bottle). On the other hand, the response of requesting water will be less likely to occur if the child just consumed two glasses of juice.

MOs are critical when designing intervention plans to teach independent living skills. For example, a young child with autism learning to pour his own juice from a container into a cup may be more likely to complete the steps accurately if there is an MO for thirst. In this example, the child may more readily acquire the steps associated with pouring his own juice when he is sufficiently motivated for juice. The teacher could, for example, teach the child to pour his juice when he is more likely thirsty, such as right after playing on the playground or after eating a salty food item.

Research is emerging that MOs can be used to teach relevant skills associated with independent living. Lechago et al. (2010) for example, used total task presentation to teach skills such as setting a table and preparing strawberry milk. MOs were created by removing an item required to complete the response chains (e.g., a spoon needed to stir the milk) in order to establish those items as effective reinforcers for asking for help in finding the items needed to complete the response. In this example the MO is used to teach an essential independent living skill (i.e., asking for assistance when needed), so that other important independent living skill (i.e., preparing a drink and setting a table) could be completed.

Given that children with autism will require intensive and extensive instruction in independent living skills, increasing their motivation for participation in these tasks is essential (Taylor and Fisher 2010). Understanding and using MOs during teaching programs for young learners with autism may enhance their participation in learning tasks, increase their overall motivation to acquire the responses associated with independent living, and increase the effectiveness of the reinforcers delivered during those teaching interactions.

Incidental Teaching

Another way to increase the motivation of children to participate in learning independent living tasks is to use incidental teaching. A full treatment of naturalistic behavioral teaching strategies is provided in the chapter entitled Natural Environment Training in this volume, but below we provide a brief overview of how incidental teaching can be particularly useful for independent living skills. Incidental teaching involves arranging the environment to increase initiations of the child toward a preferred activity or item, such as placing an item in view but out of reach of the child. This environmental arrangement along with the child's interest in the item creates an opportunity to teach a response (Hart and Risley 1982). For example, if the child leads his teacher by the hand to an item of interest, the teacher can prompt the child to engage in a response in order to gain access to the item or activity (e.g., model the name of the item for the child to imitate).

Traditionally, incidental teaching has been used to increase elaborated language of children with autism (Krantz et al. 1981). It can also be used to increase independent living skills. For example, if a child is learning to open a variety of containers (a skill necessary to complete many other independent living tasks), and initiates for a preferred snack item, his mother could place the item in a see-through jar with a closed lid. The child could then be prompted to open the container and after he does so, gain access to the preferred item in the jar. In this example, the reinforcer, a preferred snack item, is "naturally" linked to the response of opening the jar. The child may be more "motivated" to engage in the response of opening the container in order to gain access to the item and as a result learn the response readily. In another example, if a child is learning to put on her shoes and requests to play outside or go for a ride in the car, her mother could use this as a teaching opportunity and prompt her to put her shoes on before accessing the activity. Here the preferred activity initiated for (e.g., to play outside) is a reinforcer that is naturally linked to the response of putting on her shoes (e.g., she has to put her shoes on to go out).

Incidental teaching lends itself to increasing skills in very young toddlers with autism who may not be developmentally "ready" for structured and intensive teaching interactions that require heightened attention. These procedures however, will require teachers and caregivers to arrange the environment in order to increase initiations of the child with autism to provide ample learning opportunities (Fenske et al. 2001). It will also necessitate careful attention to the child's initiations as they occur naturally in the environment in order to capture opportunities to teach.

Generalization

Generalization of behavior change is essential if individuals with autism are to be fully independent in daily living skills. In fact, it may be argued that generalization is essential to independence. If a child with autism can only use the toilet at school with one specific teacher, in one specific bathroom, it is hard to imagine that child becoming fully independent with toilet training. Generalization is defined by the extent to which responses occur in the presence of similar but different stimuli, and that have not been predictive of reinforcement. For example, a child learns to brush his teeth in the school bathroom as a result of his teacher prompting and reinforcing toothbrushing, and without further training or reinforcement, the child demonstrates the response in his bathroom at home. Here the child is able to engage in the responses of toothbrushing in a similar but different bathroom. Below, we discuss several strategies that help promote generalization and how they may be implemented while teaching independent living skills.

Because we want skills to be demonstrated beyond the circumstances of training, it is important to use strategies that promote generalization throughout teaching. Stokes and Baer (1977) outlined a number of useful ways to increase generalization. One strategy is to target skills that lead to natural communities of reinforcers. Generalization to the post-intervention environment is more likely to occur if the behaviors trained lead to reinforcers readily available in the child's natural environment. For example, the skill of using a fork independently leads to the naturally occurring reinforcer of access to food. Here the reinforcer (food consumption) is naturally linked to the response of using a fork (as opposed to a teacher providing praise and access to another activity as a reinforcer), and is available across all environments. As a result, the skill of using a fork may occur and maintain in other environments because the reinforcer (food consumption) will be available. Thus, when identifying potential targets to teach young children, caregivers should first consider if the skill will lead to reinforcers readily available in the child's natural environment.

Another strategy to promote generalization is to use many examples of stimuli during the training, referred to as "multiple exemplar training." Using multiple examples in the training context can also address issues related to stimulus overselectivity. If varied stimuli are used during training, it will prevent the child with autism from overselecting on specific features of the training environment. For example, a caregiver may teach a response using a variety of stimuli, in a wide variety of settings and situations, and across a variety of people. A parent when teaching her child to put on a pair of pants for example would use several different pairs of pants, have the child put on his pants in a variety of locations within the house, and ask others (e.g., a relative) to practice the skill with the child. In this case, the child may be more likely to put his pants on at his grandmother's house because the training environment incorporated a variety of different stimuli. Thus, to enhance the likelihood that responses will occur across environments stimuli and people, many different stimuli should be incorporated into training.

Generalization can also be enhanced by using stimuli from the natural environment in the training context. This strategy, referred to as programing common stimuli, increases the likelihood that the response will occur in the natural environment because training incorporates specific stimuli that the child will come in contact with in that environment. For example, when teaching a child to brush his teeth at school, a teacher may use the same color and type of toothbrush and brand of toothpaste used at home. Because these stimuli were present during training, and predictive of reinforcement, toothbrushing is more likely to occur in the child's home with his mother, where training did not take place.

Programing for generalization for children with autism will require careful consideration of which target skill to teach, the stimuli used during training, and the contexts where the skill will be demonstrated. Rather than train a response and hope the skill will transfer to other environments, caregivers and teachers should incorporate generalization procedures to enhance generalization from the start of teaching.

Task Analysis

Many independent living skills are tasks that comprise many component responses. For example, getting dressed comprises all the steps of putting on a shirt, putting on pants, and so on. These responses are then linked in a chain. In order to know what responses comprise the chain, a task analysis is conducted to identify all the steps. Task analysis is the process of breaking a complex skill or series of behaviors into smaller, teachable units. The first step in creating a task analysis is determining the steps and sequence necessary to complete the task. Once the steps are identified, the sequence or procedure to teach each step can be individualized for the specific learner.

Cooper et al. (2007) identify three methods to identify the components of a task analysis: Observe competent individuals perform the task, consult with individuals who are experts in performing the task, or perform the task oneself. All three methods can work but performing the task oneself enables the teacher to obtain personal contact with all the responses in the chain and so this method is recommended.

Once a task is observed or performed by the teacher the steps are written down and the sequence and steps may be revised or altered. For some learners a task analysis may include very specific steps (e.g., get toothpaste, open toothpaste, get toothbrush, squeeze toothpaste on

Learner's Name: Mary S.

Program: Brushes Teeth

Criterion: 90% for 2 consecutive sessions

Reinforcement: FR-2

Prompt: Photo activity schedule and manual guidance

Step	Score each response as follows: (C) correct (I) incorrect (P) prompted																			
1. Walks to the bathroom																				
2. Gets materials (toothbrush, toothpaste, cup)																				
3. Turns on cold water																				
4. Wets brush under water																				
5. Turns off water																				
6. Removes cap from toothpaste																				
7. Holds toothbrush in right hand																				
8. Holds toothpaste in left hand																				
9. Squeezes toothpaste on brush																				
10. Puts toothpaste down																				
11. Brushes top right teeth for 10 seconds																				
12. Brushes top left teeth for 10 seconds																				
13. Brushes bottom right teeth for 10 seconds																				
14. Brushes bottom left teeth for 10 seconds																				
15. Brushes top front teeth for 10 seconds																				
16. Brushes bottom front teeth for 10 seconds																				
17. Brushes tongue for 10 seconds																				
18. Spits in sink																				
19. Puts toothbrush down on sink																				
20. Fills cup with water																				
21. Rinses mouth and spits in sink																				
22. Puts cup away																				
23. Rinses toothbrush																				
24. Puts materials away																				
25. Wipes mouth with paper towel																				

Fig. 19.1 Sample task analysis and data sheet for a toothbrushing program

brush), while other learners may not require so much detail and can be more general (e.g., "Put toothpaste on toothbrush"). A teacher may also combine individual steps together as learners become more proficient at the task. For example, the steps of getting the toothpaste container and opening the toothpaste may eventually be combined to simply, "Get toothpaste" which incorporates both steps of the chain (see Fig. 19.1 for an example of a task analysis).

After the task analysis has been developed for the specific skill and learner, the task can be taught using a variety of procedures. Commonly, response chains are taught by using one of the procedures described in detail in the following section.

Chaining Procedures

There are three commonly used procedures for teaching the component responses of a chain: Backward and forward chaining and total task prompting. The consideration of which one to use will involve multiple variables such as the skill being targeted and factors related to the learner such as his cooperation with prompts and his ability to complete multiple responses before a reinforcer is presented.

In a backward chaining procedure, the last step in the chain is taught first and the second to last step is not introduced until the child can produce that step independently (without prompts). For example, a caregiver teaching her child to put her shirt on would perform all the responses for her (e.g., place the shirt over her head, place her arms through, etc.) but would stop right before the last step (e.g., pulling the shirt down over her stomach). She would then provide an instruction such as, “Put your shirt on please,” and would then prompt and reinforce that step. Once the child is able to perform that response without prompts the second to last step (e.g., putting her left arm through the sleeve) is taught. The child would then be required to complete both steps (e.g., putting her arm through the sleeve and pulling the shirt over her stomach) before a reinforcer is provided. Backward chaining can be helpful for young children who do not yet cooperate with a lot of physical guidance (e.g., they may find too much physical guidance aversive). It can also be helpful to shape multiple responses before a reinforcer is provided.

A forward chain procedure is similar to backward chaining but starting with the first step in the chain. For example, when teaching a child to put on his shirt, the teacher would present the instruction, “Put your shirt on please,” and would then prompt and reinforce the first step (e.g., picking up the shirt). Once this response in the chain is acquired, the next step in the chain (e.g., opening the shirt to place over the head), is added to the chain and the child is expected to complete both responses before a reinforcer is presented. Again, this procedure can be helpful for young learners who are only beginning to cooperate with physical guidance.

Total task prompting would involve prompting the entire sequence of the task and differentially reinforcing component responses in the chain that occur without prompts or with the least amount of assistance. For instance, a father teaching his son to put on his shirt would say, “Please put on your shirt,” and would then prompt all components of the response and would systematically fade assistance across teaching opportunities.

When determining which chaining procedure to use, teachers and caregivers should consider: (a) the response being taught, such as determining if it is a task composed of many responses, (b) the child’s overall compliance with prompts, and (c) the child’s sensitivity to delayed reinforcement. It may be the case that for a young learner with autism, using a backward or forward chaining procedure may be best because it helps limit the amount of manual guidance used. On the other hand, a child may be able to learn a long response chain faster if all components of the response are prompted simultaneously as in the total task method. Thus, a careful consideration of the task and the learner is necessary when determining which one to use.

Fluency-Building Procedures

As mentioned earlier, in order to develop independence with many skills associated with independent living, a learner must be able to demonstrate the skill with fluency that is demonstrate speed and accuracy with the component responses of the long response chain (Binder 2010). Fluency procedures incorporate timed practice of component responses. For example, if a child is learning to complete the steps of putting on his pants and the pants have a snap, his teacher would conduct timed practice sessions of the skill of snapping. A fluency aim (a goal for how many times he should snap within a predetermined time period) is established usually by observing typical peers perform the same skill. The teacher would then arrange for a series of timed practice sessions (e.g., repeated 1 min practice sessions) until the child meets the fluency aim. To shape responding toward the aim, the rate of responding required for reinforcement is systematically increased until the aim is met (e.g., snaps 15 times in 1 min). Once the goal is reached for speed and accuracy for snapping, this response is then expected to be demonstrated within the long response chain of putting pants on. Because the child has developed fluent snapping skills, he may require less prompting for this response when completing the long response chain of putting on his pants.

Fluency procedures can be used to address the deficits in fine motor skills which can impede acquisition of daily living skills. If teachers incorporate timed practice of component fine motor responses (e.g., buttoning, snapping, zipping, twisting, open containers, and so on), it should improve performance in demonstrating the long response chain where these skills are expected (e.g., removing the cap to the toothpaste to complete the response of toothbrushing). Some researchers have argued that combining chaining procedures with procedures that increase fluency results in better acquisition and maintenance of response chains associated with daily living skills (Twarek et al. 2010). While more research is needed to demonstrate this connection, it stands to reason that teachers and caregivers should provide ample opportunities to practice component responses associated with long response chains.

Technology That Can Reduce Reliance on Teacher Prompts

As previously mentioned, children with autism may become reliant on teacher and caregiver prompts to complete self-care and daily living routines. One reason for this may be that socially mediated interventions promote reliance on prompts. For example, a child who is provided with repeated verbal prompts to complete a routine may come to rely on his mother stating each response in the chain before he completes it. Further, it may be likely that an individual with autism will always require some type of prompt or guidance to complete certain daily living routines. A goal then should be to identify prompts that are less obtrusive than adult directives and that the individual may utilize independently. It is common for typically developing adults to rely on various types of prompts to complete tasks during the course of their everyday lives. For example, we may rely on a list to complete our shopping, a video to know how to complete a recipe, and photos or instruction manuals to assemble a new bed. Similarly, individuals with autism should be taught to attend to these types of stimuli to complete tasks, thereby reducing reliance on adult prompts and increasing independence.

A number of procedures have been researched that facilitate independence and reduce dependence on adult prompts. The use of photographic activity schedules (McClannahan and Krantz 2010) is one intervention designed specifically for this purpose. A separate chapter in this volume is dedicated to photographic activity schedules but they will be briefly discussed here as they relate to independent living skills. A photographic schedule is a series of photos that represent for the learner the responses that he should perform in order to complete a task. Photos are taken of each component of the task and arranged in a photo book or in a list. For example, if a child is learning to get dressed, his father would take photos of each component of the dressing routine (e.g., a photo of a shirt to indicate he should get his shirt, a photo of his shoes, indicating he should get his shoes, and so on). He would then provide the instruction for his child to get dressed (e.g., “Get dressed please”) and would guide his son to point to the first picture in the schedule, complete the task associated with the picture (e.g., put on his underwear), and continue to guide him through the task of pointing to each picture and completing each step. Initially many prompts are provided to avoid errors and a dense schedule of reinforcement is used to teach the child to attend to the photos and to complete the routine. Eventually, only independent responses are reinforced. The goal is to shift responding from the father’s prompts to the photo schedule, thus, reducing the child’s reliance on his father’s prompts and directives to get dressed (Krantz, McDuff and McClannahan, 1993).

Video modeling can also reduce dependence on adult prompts. Video modeling requires a number of prerequisite skills such as being able to attend to and imitate a video (Taylor and DeQuinzio 2011). For independent living tasks, a video would be recorded of an adult or other child performing each step in the self-care routine (e.g., each component of toothbrushing is portrayed on the tape). The child would then watch the tape and imitate the actions on the tape. Different variations of video modeling have been researched. For example, watching each component and then performing the task or watching the entire sequence (Tereshko et al. 2010). Very young children with autism will need to be taught the prerequisite skills associated with video modeling such as imitation and attending to a video for this intervention to be effective. Nonetheless, video modeling can be an effective intervention to decrease dependence on adult mediated prompts.

Audiotaped prompts are prerecorded verbal prompts which dictate each step to complete in a chain (Mays and Heflin 2011). This intervention could be especially helpful in addressing activities of daily living where the child is unable to attend to photo or video prompts. For example, the component steps for showering (e.g., "get shampoo," "squeeze in hand") could be recorded on an audio device (e.g., an iPad) and the recording could be played just outside of the shower. For this intervention to be helpful, the child would need to be able to respond to each verbal prompt or direction on the audiotape. Like activity schedules, the child could be taught to follow the directions on the tape by being prompted by an adult to complete each step after each directive is given. Eventually, with systematic prompt fading and differential reinforcement, the directions on the tape gain stimulus control over responding and the adult should no longer be necessary to prompt the responses.

While few studies have been published to date, emerging technology such as iPads, iPods, and other handheld electronic devices could create even more opportunities to increase independent living (Cihak et al. 2010; Hammond et al. 2010; Kellems 2012). With these devices, videos, photos, and audio prompts can be recorded fairly efficiently, which will allow caregivers to modify and change the prompts as needed. It also allows teachers and caregivers to create schedules which combine all of the above components. A parent for example could have a schedule that combines a video of certain steps in a chain, photos that would prompt responses, and audiotaped directions that can be played when the child taps the photo in the schedule.

While teacher and caregiver prompts are essential to teach independent living skills, due diligence is necessary to identify prompts the can be faded efficiently and to teach children with autism to attend to and respond to prompts that will reduce reliance on caregiver prompts (e.g., photos, text, videos, etc.).

Data Collection and Analysis

Essential to any behavior change program is the continuous measurement of behavior before, during, and after training. This allows the caregiver to monitor the child's progress, to make any necessary modifications in instruction, and to ensure the skills are maintaining over time. Before data collection begins, the responses to be measured are clearly defined. Being specific in defining the behaviors in a long response chain allows for more efficient teaching and data collection. For example, the target response of using a napkin independently may be, "When presented with a meal (e.g., lunch, breakfast, dinner) and a napkin, the learner will use the napkin appropriately by wiping his or her mouth and/or hands during appropriate times (every three or four bites or when food gets on his/her mouth and/or hands) at the table." This definition is specific and includes the stimulus conditions under which the behavior should occur. Specific steps can then be identified to teach and to record data. For example, Step 1, "picks up the napkin," Step 2, "brings napkin to face," Step 3, "wipes napkin across mouth from left to right three times in a row," Step 4, "puts napkin on table." Data can then be recorded on whether each of these responses in the chain is demonstrated independently or with prompts. The percentage of steps completed accurately across opportunities can then be calculated and graphed for visual display (Fig. 19.2 provides a sample graph with hypothetical data depicting percent correct of the whole sequence of using a napkin).

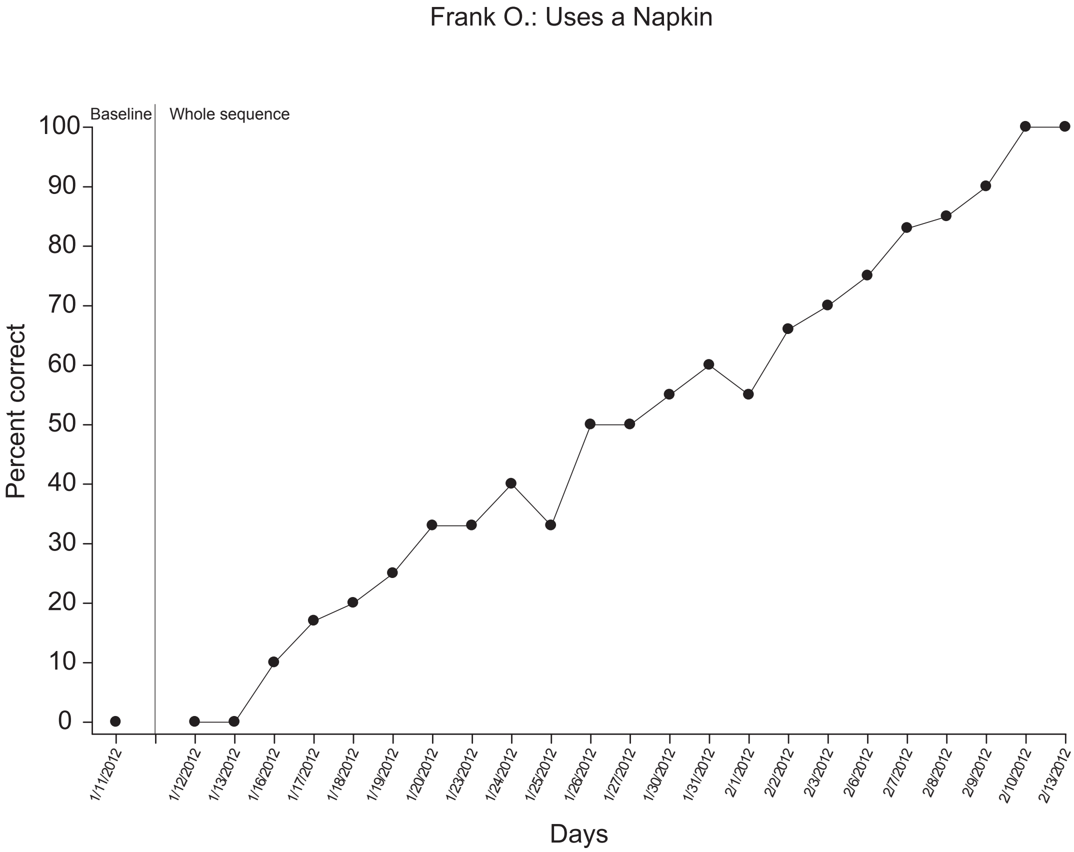

Fig. 19.2 Hypothetical data depicting percentage correct of a whole sequence of using a napkin

Data can also be collected on one of the component responses in the chain (e.g., walks to the bathroom) and the percentage of opportunities that the response was demonstrated to proficiency can be calculated and graphed. Thus, a long response chain such as toothbrushing may have two measures: Percent correct on the current step (e.g., picks up toothbrush), and percent correct on the entire sequence (e.g., a twenty-step task analysis). Over time, the whole sequence for a long response chain (e.g., toothbrushing or shoe tying) should ascend as the learner masters each individual step, and the steps are chained together. Data are then graphed to visually display the data which allows the teacher to monitor if the intervention is leading to the acquisition of the skill (Fig. 19.3 provides a sample graph with hypothetical data depicting percent correct of the component responses of toothbrushing).

Data collection, although essential, can be cumbersome while simultaneously prompting a child to complete a long response chain. For example, when teaching a child to wash parts of his body during a bath, it would be disruptive to the flow of teaching to stop and record data on each response. To address this issue, a caregiver could conduct regularly scheduled “probes” of performance without prompts and reinforcement. The caregiver could teach bathing for several days in a row and then on a predetermined schedule allow the child to bathe himself without prompts and reinforcers. During these probe sessions, data are recorded on the responses performed independently. If necessary, more teaching would take place and intermittent probes would continue to be conducted to determine if independent performance improves.

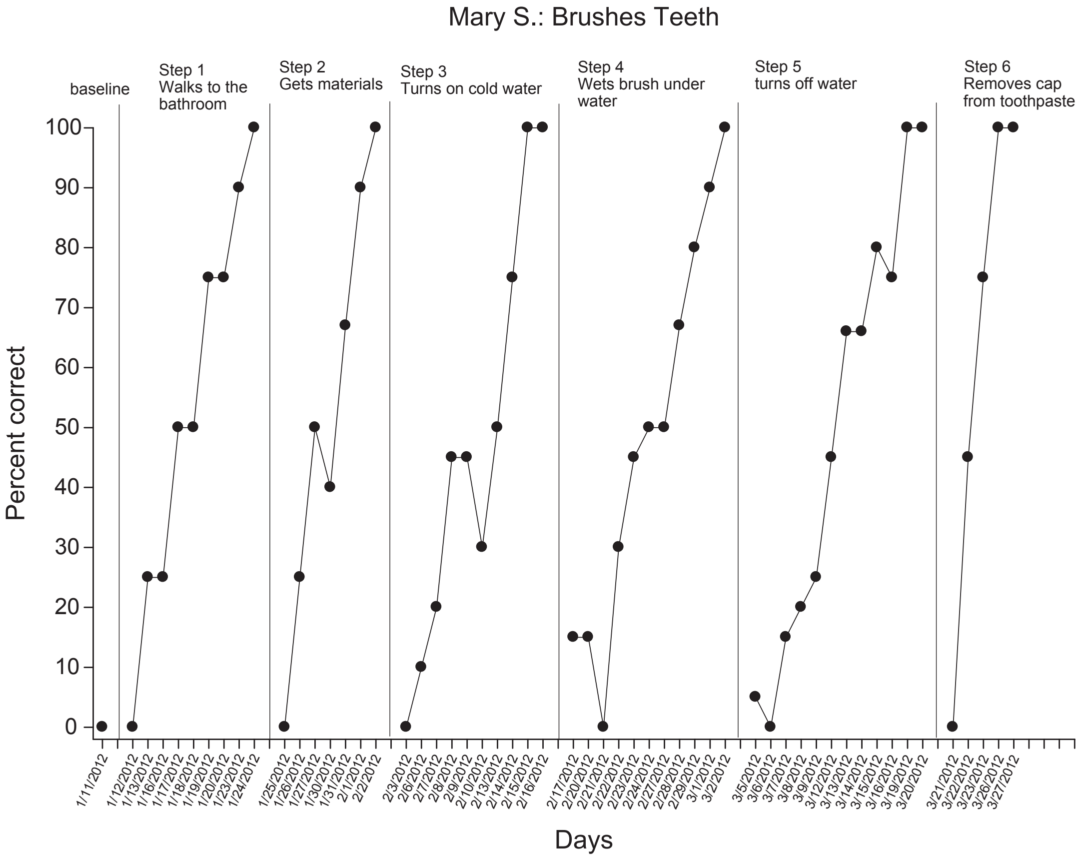

Fig. 19.3 Hypothetical data depicting percent correct of component responses of a tooth brushing sequence

Accurate and ongoing data collection allows teachers and caregivers to evaluate the effects of teaching interventions and to determine if modifications in procedures are necessary. Developing efficient data systems that do not interfere with teaching are essential to allow instructors to focus on shaping during the teaching interaction.

Targeting Independent Living Skills with Young Children with Autism

Assessment and Use of Developmental Norms to Identify Target Skills

Resources such as the Centers for Disease Control (2011) provides information regarding developmental norms related to many early childhood repertoires, such as independence and self-care skills. These lists may serve as helpful guides to identify age-appropriate targets to teach. For example, such resources answer questions such as, “What are two year old children able to do without adult assistance?” Additionally, there are published curricula that suggest self-care skills to teach (e.g., Anderson et al. 2007; Baker and Brightman 2004; www.skillsforautism.com) and standard assessment protocols such as the Vineland Adaptive Behavior Scales (VABS) (Sparrow, Cicchetti and Balla 2005) and the Scales of Independent Behavior (SIB-R) (Bruininks et al. 1996) can be used to identify specific target skills. See also the chapter on Linking Assessment to Curricula in this volume for an in-depth discussion of various curricula and assessments currently available.

Foundation Skills and How They are Linked to Target Skills

While an exhaustive list of skills to target in the area of independent living is beyond the scope of this chapter, there are a number of foundation skills that will set the stage for learning more complex repertoires of independent living. Below are a few of the foundation skills that can be targeted in early intervention programs for young learners with autism.

Cooperating with manual guidance Acquiring independent living skills will require a good deal of prompting from caregivers. Children with autism however, may find manual guidance initially unpleasant and as a result may engage in avoidance or escape-related behavior when prompted. If this is the case, the child should be taught to cooperate with prompts. This can be taught by shaping the child's cooperation with prompts. Initially, the teacher would just touch the child's hand and provide a reinforcer. She may then apply more pressure to the child's hand, or lift the child's hand up before providing a reinforcer. Over the course of teaching sessions, she would differentially reinforce the child's cooperation (e.g., not pulling away or escaping) with more intrusive prompts (e.g., guiding his hands to complete a fine motor action). Initially, motivation to cooperate with prompts can be enhanced by guiding the child to complete tasks that are inherently motivating such as how to press the buttons on a "cause–and-effect" toy. Once the child is able to cooperate with prompts to complete fun and interesting activities, he may be more likely to cooperate with prompts to complete self-care routines.

Imitating Many self-care and daily living tasks will be regularly modeled in the child's natural environment. For example, a child may be playing with his toys in the kitchen as his father is setting the table. If a child is proficient in imitation, learning can be facilitated through the use of modeling prompts. Most children with autism however, do not have well-developed imitative skills. Efforts should be made to teach children with autism how to imitate a variety of actions, both gross and fine motor, and to reproduce those actions after the model is no longer present. Most early curricula for children with autism address basic imitative skills (e.g., gross motor imitation), but focus should also be on imitating more complex behaviors such as imitation of sequences, retention of imitative behavior, and imitation of peer behavior. For children with autism, motivation for imitation can be enhanced by teaching imitative responses that lead to a desired outcome. For example, rather than teaching a child to roll a car back and forth when he may have no interest in cars, the teacher could teach him to imitate behavior that leads to an outcome that he is interested in such as imitation of how to operate a preferred toy. By expanding imitative repertoires, children with autism may come to acquire some skills without explicit instruction from an adult and even if outright observational learning does not occur, future efforts at teaching the child will be enhanced if modeling prompts can be used successfully.

Completing tasks with a beginning and end Most daily living tasks will have a start and finish and will require sustained engagement across the task (e.g., toothbrushing has a beginning and end point). As such, it would be important to teach children with autism in the toddler and preschool years to start and finish activities. These activities can be age-appropriate play activities such as learning to start and complete a shape sorter or to complete simple puzzles. Backward chaining procedures can be used to shape these responses. For example, a father teaching his daughter to complete a puzzle would begin with only one piece out of the puzzle to place in. He would present the instruction to complete the puzzle, guide his daughter's hand to place the puzzle in, and provide a reinforcer. Eventually, as his daughter is independent he would remove additional pieces to place in the puzzle until eventually the child is completing the entire puzzle without his prompts.

Independent sustained engagement While children with autism may show preference for engaging with a select number of items, their ability to sustain engagement across a variety of productive activities is limited. Additionally, independent living skills will require sustained engagement to complete the task. Efforts then should be made to teach children with autism to maintain engagement in a variety of activities for longer and longer periods of time. For example, a teacher may use shaping to increase the duration of time a child sustains engagement with toys. Initially, the teacher would set a timer for 1 min (or less time if necessary) and prompt and reinforce the child to play with a toy until the timer rings. Eventually, the teacher would fade her prompts and proximity to the child until the child is sustaining engagement independently until the timer rings. Over time, the length of time the child is expected to sustain engagement with the toy can be increased. The teacher would also increase her distance until the child is able to play with toys for longer durations without the teacher being present. Learning to engage with tasks for appropriate periods of time—without direct adult supervision, may set the occasion for the child to learn to perform daily living tasks independently in the future.

Photo-reading skills If the skill is not already present, efforts should be made to teach young children with autism the correspondence between photos and objects in their environment and actions. This skill will aide in learning to follow photographic activity schedules to complete independent living skills and is necessary for a variety of situations in daily life, such as picture books, menus, etc. After learning to match identical 3D objects, a child could be taught to match objects to a corresponding photo. The child can then be taught to point to a photo and get the corresponding object. Eventually, the photos could also be actions (e.g., a photo of someone clapping) and the child could be taught to match the action (e.g., clap when he pointed to the photo). Eventually the photos could be placed in a photo book or in an iPad touch schedule and the child could be taught to reference the photo and complete the corresponding action.

Completing gross and fine motor skills Gross and fine motor skills are often necessary foundation skills for the learning and performance of more complex independent living skills. Prior to instruction, it might be beneficial to ensure that young learners with autism can perform responses such as buttoning, snapping, zipping, twisting caps, squeezing tubes, and opening lids to fluency before embedding them in longer response chains. These component responses are directly related to the performance of longer response chains such as dressing, brushing teeth, and preparing a simple task.

Requesting for items and assistance Research indicates that most individuals with autism will require intervention across their life span. As such, it is likely that they will require some assistance with self-care and daily living activities. It would be essential then to teach the individual with autism to identify the contexts where assistance is needed, and to engage in responses that recruit adult assistance when necessary. Teachers and caregivers should implement instructional programs to develop a functional system of communication for the child with autism (see chapter on Verbal Behavior in this volume). Whether it is improving a child's vocal verbal behavior or teaching him to use an augmentative communication system, the child should be taught the vocabulary associated with independent living skills (e.g., tacts for items necessary to complete self-care routines), as well as responses that would recruit adult assistance (e.g., mands for assistance to complete these routines). For example, a child may have learned to complete all the steps of getting dressed but despite his parents' best efforts at teaching, he continues to put his shirt on backwards. In this example, rather than spend additional time teaching him that the "tag goes in the back," his parents could teach him to ask them to check his appearance when he is finished dressing. The child could for example, be taught to approach his mother and say, "How do I look?" His mother could then provide him with further instructions if necessary to turn his shirt around (e.g., she could say, "You look great, but don't forget to turn your shirt around.").

Teaching young learners with autism to request assistance can begin with teaching them to request preferred items, to request for the location of items, and to request assistance with manipulating and operating items and toys of interest. For example, a child can be given a preferred puzzle to complete and the teacher could remove parts of the puzzle. When the child indicates that he cannot find the missing pieces, his teacher could prompt him to ask where the pieces are. In another example, a father could provide his child with a toy that she is interested in but is unable to operate herself. Her father could then prompt her to say, "Help me" when she is indicating that she cannot operate the toy herself. Teachers and caregivers can arrange the environment and can capture and contrive MOs to teach the verbal behavior associated with assistance seeking (Sundberg et al. 2001). By knowing the conditions in which assistance will be needed and knowing how to recruit that assistance, the overall independence of the child with autism will be increased.

Future Directions

Research in the area of applied behavior analysis indicates that children with autism can learn a wide variety of skills that improve independent functioning in daily life. Many for example can learn to communicate, to interact socially with friends and family, and to perform many adaptive behaviors associated with independent living. Research and curriculum development in identifying the essential skills to teach young learners with autism to improve outcomes related to independent living continues however, to be a work in progress. If the current research indicates that the majority of individuals with autism will require some level of support and supervision into the adult years, early learning curricula must focus on ways to improve overall independence of the child with autism. This will likely require a reprioritization of some curriculum targets and a close examination of the strategies employed to promote independence. It may be the case that skills essential to be more independent in the adult years will require more focused attention in the early years. And, while we can infer that many procedures outlined to teach independence for young adults may be appropriate for teaching toddlers, more research is needed to identify effective and efficient procedures to address these specific skills in younger children with autism. Nonetheless, the field of applied behavior analysis offers teachers and caregivers a promising cache of instructional strategies to improve the overall outcome of individuals with autism.

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20 Developmental Approaches to Treatment of Young Children with Autism Spectrum Disorder

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Keywords

Autism Treatment · Denver Model · Developmental Approach · DIR Floortime · ESDM · JAML · JASPER · Milieu Teaching · More than Words · RDI · RPMT · Responsive Teaching · SCERTS · TEACCH

Children with autism/autism spectrum disorder (ASD) demonstrate impairments in social, language, motor, and usually cognitive domains of development, and they often have some stereotyped and repetitive behaviors, with symptom patterns that may change considerably across their lives. In 1972, Rutter classified autism as a developmental disorder and the field began to appreciate the value of a developmental approach to evaluation and treatment (Ozonoff and Rogers 2003; Rutter 1972). Autism is now understood as a developmental disorder of neurobiological origin (National Research Council (NRC) 2001) and is defined as a "pervasive developmental disorder," a term that emphasizes "the pervasiveness of difficulties across various domains of development as well as the important developmental aspects of these conditions" (Koenig et al. 2000).

Taking this developmental perspective one step further, Gillham et al. (2000) argued for a developmental operational definition of ASD that considers the range of syndrome expression within a developmental context, which categorical definitions of ASD fail to do. The (American Psychiatric Association 2013) revisions of the diagnostic criteria for ASD in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders do, in fact, move to a single spectrum disorder that considers the severity of each individual's symptoms in the core domains and specifically recognizes the importance of the child's developmental level when considering a child's ability to develop and maintain relationships. (The terms "autism" and autism spectrum disorder (ASD) will be used interchangeably in this chapter.)

Not only have the definition and the etiology of autism evolved to include a developmental perspective over time, but developmental approaches to treating autism in young children have developed as well. Schopler and Reichler (1971) created an early "developmental therapy"—now the TEACCH approach, defined later—to treating autism in young children. This treatment model focused on the unique impairments of each child

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and viewed parents as the "most effective developmental agents for their children" (Schopler and Reichler 1971, p. 99). Many other developmental approaches to treating autism in young children have been created since that time, and more and more studies are being conducted to determine the efficacy of these approaches.

In fact, treatment recommendations by the NRC for efficacious ASD interventions include several explicitly developmental considerations: beginning soon after diagnosis, including *developmentally appropriate* activities to meet identified objectives, being intensive with 25 h or more of treatment each week, working toward meeting *individualized goals* in a planful way, *including the family* by incorporating a parent training component, including ongoing program evaluation and *assessment of the child's developmental progress,* and including opportunities for the child to be in *inclusive settings* (emphasis added; NRC 2001).

The main purpose of this chapter is to provide the reader with a review of the empirical work published on the major developmental treatment approaches for young children with autism to assist with selection of appropriate, empirically supported interventions for young children with ASD and their parents.

Defining Developmental Approaches to ASD Treatment

In the field of early autism intervention, there is not yet agreement about the criteria that comprise the definition of a developmental approach. The hallmarks of developmental approaches described in the literature are twofold: the application of the principles of developmental science within the intervention, and the use of typical developmental sequences as the framework for assessment and program planning (Corsello 2005; Rogers and Ozonoff 2006; Rogers and Wallace 2011; Vismara and Rogers 2010; Wetherby and Woods 2008; Wieder and Greenspan 2001). Some previous reviews of developmental approaches to ASD treatment only consider the incorporation of developmental science as the integral component (e.g., Ospina et al. 2008); however, the majority of reviews and experts in the field of autism intervention include both criteria.

Developmental approaches base assessment and treatment program planning on sequences of typical child development. In doing so, they recognize the uniqueness of each child's developmental profile and learning needs and create a framework for individualized program planning. Developmental approaches can be applied systematically, via assessing, developing learning objectives, and systematically teaching skills in the sequence in which typically developing children learn (Vismara and Rogers 2010).

Developmental approaches also typically embrace attachment theory and science concepts concerning the importance of high quality adult–child relationships marked by adult sensitivity and responsivity to children's cues for optimum child learning. Developmental approaches are typically constructionist models of child learning, in which children's spontaneity, initiative, interests, and motivations are encouraged and reciprocal social interactions are considered critical opportunities for learning. Adults support and encourage rather than direct child learning.

Previous reviews of treatment approaches for young children with ASD have conceptualized a dichotomy between behavioral approaches and developmental approaches (Ospina et al. 2008; Pajareya and Nopmaneejumruslers 2011). Behavioral approaches stem from the science of learning, whereas developmental approaches stem from developmental science. The dichotomy between behavioral and developmental approaches is appropriate if one is only considering behavioral approaches in their pure form (i.e., discrete trial training based upon applied behavior analysis (ABA) as described by Lovaas in his 1987 seminal paper). However, most community-based programs utilizing discrete trial training and applied behavior analysis (ABA) now incorporate many additional components that could be considered "developmental," including a focus on developmental prerequisites to speech and language (e.g., joint attention and gestural communication) and the use of developmental skills inside discrete teaching (Lifter 2008).

Children's learning can often be validly interpreted through both the lenses of ABA and developmental science. It has been well demonstrated that infants (as well as children and adults) are both operant learners and respondent learners. The fact that certain developmental skills emerge in an ordered fashion and build on prior abilities nevertheless assumes that learning is occurring as children master new developmental skills, and that both operant and respondent processes are at work. As representational capacities develop, they provide additional tools for learning but the laws of operant and respondent learning apply to representations as well as to sensory motor behavior, as is so clearly seen in phobias and obsessive compulsive disorders. Thus, developmental growth and operant learning are not separate in nature, and their separation in early intervention for ASD is likely working against us.

Methods for Systematic Literature Review

A number of comprehensive research reviews have reported the efficacy of different ASD treatment approaches (e.g., Eikeseth 2009; McConachie and Diggle 2007; Odom et al. 2010; Ospina et al. 2008; Rogers 1998; Rogers and Vismara 2008; Rogers and Wallace 2011; Smith 1999; Vismara and Rogers 2010; Wallace and Rogers 2010; Warren et al. 2011). Of particular importance to note is Wetherby and Wood's (2008) review that focuses specifically on developmental approaches to treating autism in infants and toddlers. The current chapter will build upon Wetherby and Wood's review by including studies for children up to 5 years of age.

Although the National Association for the Education of Young Children (NAEYC) has defined the "early childhood period" as birth to 8 years of age (Bredekamp and Copple 1997), the following literature review includes studies of approaches for infants, toddlers, preschoolers, and children of kindergarten age, before children are participating in autism treatments designed for "school-aged" students.

This review was conducted using a systematic strategy developed a priori. A list of developmental approaches was compiled by collecting the names of treatment approaches reviewed in the ASD treatment efficacy review articles and chapters cited in the beginning of this section. In addition, we entered the following combinations of keywords into the psychological, educational, and medical search engines PSYCINFO, ERIC, and PUBMED: "*developmental treatment*" or "*developmental approaches*" or "*developmental intervention*" combined with either "*autism*" OR "*ASD*." This search strategy primarily identified treatment approaches that have been "branded" with a consistent treatment name and have an accompanying treatment manual (e.g., Rogers and Vismara 2008).

Once the names of the major developmental treatment approaches were identified, the third author reviewed the list to ensure that it was comprehensive. This resulting list of ten treatment approaches was used in our secondary search. The secondary search included a separate search for peer-reviewed journal articles within each treatment approach. The name of the treatment approach was entered as a keyword along with the keywords "*autism*" or "*ASD*." A limitation of this search strategy was that treatment studies conducted before the treatment approach was formally named were unlikely to show up in the results; consequently, these studies are likely to be omitted from this review. The advantage of using treatment names in the search criteria is that studies reviewed reflect the branded treatment approach and treatments that have been branded are further along in their own development and are more likely to be administered in a consistent manner from one study to the next.

The next step in our review involved excluding studies that did not meet our inclusion criteria. We excluded studies in which the minority of subjects was in the targeted age range. In addition, we excluded papers that were descriptive rather than data based, so that only studies exploring the efficacy of the treatment approach were included in our final analysis. Finally, we excluded papers that had not been published in peer-reviewed journals.

Each treatment approach identified in the systematic search was reviewed on two levels. First, the research studies for each approach and the accompanying treatment manual (if applicable) were read to determine, on a global level, how many developmental components each treatment approach encompassed (see *Review Level 1* below). Next, each study that met search criteria was reviewed using Nathan and Gorman's (2002, 2007) criteria for establishing empirical support (see *Review Level 2* below). Each of these levels of review is described in detail below.

Review Level 1: Identification of Developmental Components of Treatment Approaches

In order for an intervention approach to be considered "developmental" and included in this review, the approach need only be self-identified by its creators as developmental. Thus, several approaches that some have considered developmental are not covered here because they were not self-identified as being so, including the EarlyBird Programme, LEAP, Son-Rise, the Walden Program, Pivotal Response Training, and the Scottish Centre for Autism Preschool Treatment. There were several additional commonalities among the developmental approaches, and we indicated the presence or absence of these as well in our review.

1. *Following the sequence of typical development:* While much has been debated in the field regarding developmental delay versus developmental deviance in autism (Carpenter et al. 2002), developmental treatment approaches generally reference typical developmental sequences when planning intervention. They consider the unique developmental difficulties expressed by children with autism and then tailor treatment to meet each child's individual developmental profile and strengths (Burack et al. 2001; Wetherby and Woods 2008).
2. *Using principles of developmental science:* Developmental treatment approaches generally incorporate the knowledge gleaned from developmental science to inform the intervention (Burack et al., 2001). For example, approaches may take into account current research on typical language development to inform the contexts or the functions in which language development is targeted and the strategies used to facilitate language development for young children with ASD.
3. *Relationship based:* Developmental treatment approaches are often delivered in the context of meaningful interpersonal relationships between adult and child and the quality of adult–child relationships is often directly considered in the treatment approaches (Greenspan and Wieder 1997; Sandall et al. 2000; Stern 1985).
4. *Child-centered:* Developmental treatment approaches are often child-centered and reciprocal. The child is often viewed as an active (not passive) participant in his/her learning (Piaget 1954). Often, either the parent or the therapist follows the child's lead in delivering the intervention by honoring the child's choices and interests (Mastergeorge et al. 2003; Siller and Sigman 2002), or the child and adult share control, interact reciprocally, and co-construct activities (Rogers and Dawson 2010; Siller and Sigman 2002).
5. *Play based:* Developmental treatment approaches are often play based, as play is the context in which young children typically learn (Lifter 2008; Rogers 2005; Vygotsky 1978).

The presence or absence of these components in each of the developmental approaches reviewed in this chapter is noted in Table 20.1. In addition, the following features of each treatment approach were also considered and included in this table:

a. *Is the treatment comprehensive or targeted?* Comprehensive treatment approaches address multiple domains of development for children with ASD (Eikeseth 2009; Odom et al. 2010; Rogers 1998; Stansberry-Brunsnahan and Collet-Klingenberg 2010; Vismara and Rogers 2010; Wetherby and Woods 2008). In contrast, targeted approaches focus on supporting "pivotal developmental behaviors," "foundational behaviors" (Mahoney and Perales 2003, 2005), or "developmental precursors" (Schertz and Odom 2007), such as attention, persistence, interest, initiation, cooperation, joint attention, imitation, symbolic play, or affect, which are core deficits that are believed

Table 20.1 The developmental components of ASD treatment approaches—six core criteria and three additional considerations

Developmental approach	1. Sequence of typical development?	2. Principles of developmental science?	3. Relationship based?	4. Child-centered?	5. Play ased?	A. Comprehensive or targeted?	B. Delivered by therapists, parents, or both?	C. Delivered in a naturalistic setting or a clinic-based setting?
Denver Model/Early Start Denver Model (ESDM)	Y	Y	Y	Y	Y	Comprehensive	Both	Both
Developmental Individual-Differences, Relationship-based (DIR/Floortime)	Y	Y	Y	Y	Y	Comprehensive	Both	Both
Hanen's More than Words	Y	Y	Y	Y	Y	Targeted (communication/language)	Parents	Naturalistic
Joint Attention Mediated Learning (JAML)	Y	Y	Y	Y	Y	Targeted	Parents	Naturalistic
Joint Attention and Symbolic Play Engagement Regulation (JASPER)	Y	Y	Y	Y	Y	Targeted	Both	Clinic based
Relationship Development Intervention (RDI)	Y	Y	Y	Y		Comprehensive	Parents	Naturalistic
Responsive Education and Prelinguistic Milieu Teaching (RPMT)/Milieu Teaching	Y	Y		Y	Y	Targeted (communication/language)	Both	Naturalistic
Responsive Teaching (RT)	Y	Y	Y	Y	Y	Comprehensive	Parents	Naturalistic
Social Communication, Emotional Regulation, and Transactional Support (SCERTS)	Y	Y	Y	Y	Y	Comprehensive	Both (and teachers)	Naturalistic (preschool classroom)
Treatment and Education for Autistic and related Communication Handicapped Children (TEACCH)		Y	Y	Y		Comprehensive	Both	Both

to have cascading effects upon cognitive, language, and social-emotional development (Koegel et al. 1989; Mundy et al. 1990).

b. *Is the treatment delivered by therapists, parents, or both?* The inclusion of parents in a developmental treatment approach is a critical part of the relationship-based focus. In addition, training parents to deliver the intervention during daily routines often means that the intervention can be implemented at younger ages and at more intensity (Mahoney and Perales 2003, 2005; McConachie and Diggle 2007; Prizant et al. 2003; Schertz and Odom 2007; Wetherby and Woods 2006).

c. *Is the treatment delivered in the child's natural setting or is it delivered in a clinic setting?* Many developmental treatment approaches focus on implementing the intervention in a child's natural environment, a requirement of the Individuals with Disabilities Education Improvement Act of 2004, Part C (e.g., home, childcare center, or preschool; Prizant et al. 2003; Wetherby and Woods 2006; IDEA 2004). However, other approaches focus on first teaching skills in a highly structured learning environment and then working with the child to generalize these skills to other more complex, naturalistic settings (Dawson and Osterling 1997). Regardless of the teaching environment, the goal of all early intervention approaches for young children with autism is to increase the child's ability to actively and meaningfully participate in his/her family and community environments (Sandall et al. 2000).

Review Level 2: Criteria for Establishing Empirical Support for Treatment Efficacy

In addition to considering the developmental components of each treatment approach, we critically analyzed efficacy studies using Nathan and Gorman's (2002, 2007) criteria for establishing empirical support. Following Rogers and Vismara's (2008) review on comprehensive ASD treatments, we have added additional criteria to those of Nathan and Gorman. The criteria are as follows:

Type 1 studies Prospectively designed randomized clinical trials that include blind assessments, inclusion/exclusion criteria, state-of-the-art diagnosis, adequate sample sizes to power the analysis, and clearly described statistical methods. In addition, we expect Type 1 studies to include measures of treatment fidelity to determine the degree to which the treatment delivery adheres to the treatment model (Rogers and Vismara 2008; Stansberry-Brusnahan and Collet-Klingenberg 2010).

Type 2 studies Clinical trials with a comparison group, and single-subject designs in which there is clear experimental control over the dependent variable. Type 2 studies have some significant flaws, but the overall study design is such that the data can still be used to answer the study question, therefore providing useful information regarding the effectiveness of the intervention.

Type 3 studies Studies with significant methodological flaws, including studies with pre/post designs without a control group, single-subject studies with designs that do not clearly demonstrate experimental control over the dependent variable, and studies with retrospective designs.

Type 4 and 5 studies Secondary analysis articles (not included in this review).

Type 6 studies Case reports (not included in this review). To establish inter-rater reliability on the Nathan and Gorman (2002, 2007) criteria, both the first and second author independently rated 20 % of the studies. Inter-rater reliability for classification of study type was 100 %. Reliability for the seven criteria (randomization, inclusion and exclusion criteria, use of standardized diagnostic batteries, comparison group, blind assessors, treatment of fidelity, and use of a treatment manual) was 82.5 %. All disagreements were a result of the case in which one rater assigned a "+/−" rating and the other either a "+" or a "−" rating only.

Given the large number of studies available for some treatment approaches, we decided to limit the papers to at most three per approach and to prioritize Type 1 and Type 2 studies if they were available. Table 20.2 provides an overview

Table 20.2 Criteria for establishing empirical support for treatment efficacy (Nathan and Gorman (2002, 2007)

Author(s) and Year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002, 2007) criteria
Denver Model/Early Start Denver Model (ESDM)					
Rogers et al. 2006 (Denver Model)	10 ss, aged 20–65 mos.; all male; all nonverbal	Collected within 3 weeks of last tx session: ADOS, SCQ, MSEL, VABS–Interview Edition, CDI, intervention hx, play-based speech probes; collected during weekly tx sessions: speech samples; collected at 3 mos.	Single-subject design (A-B-A) using randomization to either Denver Model or PROMPT; 12 weekly 1-h sessions; for Denver Model condition, parents were present and active in sessions, and were expected to deliver treatment objectives 45 min/day; for PROMPT condition, parents observed sessions via video, and were expected to work on children's word development 30 min/day	No differences in acquired lang. skills by group; by end of tx, 8/10 children used 5+novel, functional words spontaneously and spoke multiple times per hour	Type 2 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery,+Comparison group, +Tx fidelity, +Tx manual
Vismara et al. 2009 (ESDM)	8 ss, aged 10–36 mos., seven had diagnosis of autism; one child diagnosed with autism at 18 mos. at conclusion of tx but showed significant signs consistent with autism at time of enrollment	Coding of parent–child play and therapist-child play for number of spontaneous functional verbal utterances and imitative acts; ADOS and MSEL; CBRS; ESDM Fidelty Scale for parent implementation of model	Nonconcurrent multiple baseline design; parents attended 1-h clinic visit/week for 12 weeks to receive one-on-one parent training in ESDM	Child's production of spontaneous functional verbal utterances increased w/ parent and therapist once tx began; 7/8 children demonstrated consistent increase in imitative behaviors; number of children's spontaneous verbal utterances showed largest gain once parents met ESDM fidelity; 7/8 parents acquired mastery of ESDM techniques at fidelity level of 85 % or above by 6th tx session and maintained through follow up	Type 2 study: −RCT, +/-Blind assessments (not blind to tx, but blind to order of session), +Incl/excl criteria, −Standardized dx battery, −Comparison group, +Tx fidelity, −Tx manual

Table 20.2 (continued)

Author(s) and Year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002, 2007) criteria
Dawson et al. 2010 (ESDM)	48 ss, aged 18–30 mos.; 3.5 males for every 1 female in study; diagnosed with ASD or PDD-NOS; stratified randomization on basis of composite IQ at entry	Collected at study entry and then at the end of 1 year of tx and 2 years of tx: ADI-R, ADOS, MSEL, VABS-Interview Edition, RBS	Randomized to either ESDM group or A/M community tx group; ESDM condition included: 2-h session with trained therapist 2X/day 5 days/week for 2 years (actual mean h = 15.2 h/wk), parent training 2X/mo and were expected to use ESDM strategies during daily activities (actual mean h = 16.3 h/wk), multidisciplinary team, individualized tx objectives; A/M community condition included: comprehensive diagnostic evaluations, referral to community providers for intervention commonly available in the community (actual mean h of individual tx = 9.3 h/wk) (actual mean hrs of group tx = 9.3 h/wk)	At end of 2 yrs. of tx ESDM group showed significantly improved cognitive ability (MSEL) mostly due to receptive and expressive language improvements and significantly improved adaptive behavior (VABS) when compared to A/M group; children in the ESDM group were more likely to experience a change in diagnosis from autism to PDD-NOS than A/M group	Type 1 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, +Tx manual
Developmental Individual-Differences, Relationship-Based Model (DIR/FLOORTIME)					
Hilton and Seal 2007	2 ss, aged 2 yrs; monozygotic twin brothers	CBCS; coded videos of sx for communication and behavior data; mother's journal recorded tx sessions and perceptions of child progress	One twin received DIR and one received ABA; each received 2 1-h weekly sessions administered by clinicians; 16/18 sessions each; both also received speech therapy 2X/wk	Slight gain in communication composite score for ABA child and slight loss for DIR child; contrasted gains and losses in 6 of 7 CSBS subscales; coded behavioral data showed increase in number and duration of crying episodes in ABA child, but none in DIR participant	Type 3 Study: +RCT, +/-Blind assessments (-for CSBS, + for video coding); −Inc/excl criteria, −Standardized dx battery, +Comparison group, −Tx fidelity, +Tx manual

Table 20.2 (continued)

Author(s) and Year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002, 2007) criteria
Pajareya and Nop-maneejumruslers 2011	32 ss, aged 2–6 yrs of age; all met DSM-IV criteria for autistic disorders; 8:1 male to female ratio	Primary outcome measure: FEAS; CARS; and FEDQ	Added new DIR/Floortime tx to see if there would be additional benefits over routine clinical care; stratified random assignment based on age and symptom severity; control group got typical treatment as usual in Thailand (20–40 h of ABA), experimental group got supplemental DIR Floortime tx administered to parents (no direct contact with children in this condition); 1 day training workshop + 3 h DVD lecture + 1.5 h one-on-one session, families to deliver 20 h/week of tx at home (actual amount = 15.2 h/wk);	Intervention group showed significantly greater decrease in overall autistic severity w/ CARS; statistically significant gain in FEDQ filled out by parents; parents who added in home DIR/Floortime for 10 h+/week had better tx delivery fidelity than those who did less, but not sig. difference	Type 1 study: +RCT, +Blind assessments, +Incl/excl criteria, −Standarized dx battery, +Comparison group, +Tx fidelity, +Tx manual
Solomon et al. 2007	68 ss, aged 18 mos to 6 yrs at time of diagnosis with autistic disorder, PDD-NOS, or Asperger's syndrome	FEAS caregiver and child sections; subjective ratings by home consultants on 6 pt scale of Greenspan's functional developmental levels (FDL); parent satisfaction of PLAY project on 4-pt Likert scale	PLAY Project Home Consultation Project = 1 day parent training workshop; 3–4 h/monthly home visits by consultants for parent training, videotaping, and child assessment; parent-led tx for min of 15 h/week; tx given for 1 year	No change in parents' FEAS scores before and after PLAY; increase in child's total and scaled FEAS scores over 1 year period; 45 % of children made "good" to "very good" functional developmental progress; overall parent-reported satisfaction with PLAY project was 90 %	Type 3 study: −RCT, +Blind assessments, +Inc/excl criteria, −Standardized dx battery, −Comparison group, +Tx fidelity, +Tx manual

Table 20.2 (continued)

Author(s) and Year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002, 2007) criteria
Hanen's More than Words					
Carter et al. 2011	62 ss, aged 15–25 mos.; 51 male, 11 female	At 5 mos. post-enrollment: parent–child free play procedure, ESCS, Parent Interview for Autism-Clinical Version; at 9 mos. post-enrollment: parent–child free play procedure, ESCS, Parent Interview for Autism-Clinical Version, MSEL; VABS Second Edition, ADOS, clinical DSM-IV impression	ss randomized to HMTW or "business as usual" control group; HMTW provided over 3.5 mos., consisting of eight group sxs w/ parents only and 3 in-home individualized parent–child sx; focus on: (a) improved 2-way interaction, b) more mature and conventional ways of communicating, (c) better skills in communicating for social purposes, and (d) improved understanding of lang.	No main effects of HMTW on parental responsivity or children's communication; decent effect sizes for improvements in parental responsivity; treatment effects on child communication gains to 9 mos. post-enrollment that were moderated by enrollment object interest	Type 2 study: +RCT, −Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, −Tx manual
McConachie et al. 2005	51 ss with ASD, 26 parent–child dyads in tx group and 25 parent–child dyads in control group	MCDI; social communication skills from ADOS-G; parent outcome measures on parent tx fidelity, family resources, and stress	20 weeks of group instruction 1 h/week using the More than Words Program and three home visits	Children in the training group had significantly larger vocabulary size, but no sig. differences in social communication algorithm of the ADOS-G	Type 1 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, +Tx manual
Prelock et al. 2011	4 ss, aged 37–69 mos.	3–4 mos. post-tx: CSBS DP (both caregiver questionnaire and examiner's observations), MCDI: Words and Gestures or Words and Sentences, parent responsiveness and parent satisfaction questionnaire, MSEL	Single-subject design; orientation session and 8 2.5 h sessions; clinic based; included parents in didactic and interactive manner; parents taught strategies to increase communication opportunities and interaction w/ their children, and parents developed own "to-do-at-home" plans	For 3/4 children, improvements on social and symbolic communicative acts and vocabulary, but not on MSEL; 4th child was tested differently due to his more advanced initial profile–he showed notable improvement on Mullen scores, but scored in average range both pre- and post-tx	Type 3 study: −RCT, −Blind assessments, −Incl/excl criteria, +Standardized dx battery, −Comparison group, −Tx fidelity, +Tx manual

Table 20.2 (continued)

Author(s) and Year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002, 2007) criteria
Joint Attention Mediated Learning (JAML)					
Schertz and Odom 2007	3 ss, aged 20–28 mos. diagnosed with early ASD as dx by the M-CHAT, PDD-ST-II, & ISCQ	Coded video tapes of weekly 10-min parent–child interaction for four joint attention behaviors: (1) focusing on faces; (2) turn taking; (3) responding to joint attention; (4) initiating joint attention; qualitative data from weekly sx, parent interviews, and parent notes	Parent training in families' homes based on JAML manual (4 phases of tx to increase 4 joint attention behaviors); families received between 11 and 16 tx sx over 9–26 weeks	Single-subject, multiple baseline design; changes in child performance were reflected as the number of 10-s intervals during weekly 10-min videos in which the child engaged in four joint attention behaviors; in tx condition, each of 3 toddlers surpassed baseline performance levels for all 4 targeted outcomes; 2 of 3 toddlers demonstrated repeated joint attention by end of tx	Type 2 study: −RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, −Comparison group, +Tx fidelity, +Tx manual
Joint Attention and Symbolic Play Engagement Regulation (JASPER)					
Kasari et al. 2006	56 ss, aged 3–4 yrs. with ASD as dx by the ADOS and ADI-R	MSEL, ESCS, Structured Play Assessment, Reynell Developmental Language Scales, and 15 min. caregiver-child interaction videotaped and coded for child's play behaviors, types of functional and symbolic play acts, and the joint attention skills of the dyad	Direct therapist-child intervention in the clinic focused on either joint attention skills (JA group) or symbolic play skills (SP group); 30 min per day for 5–6 weeks (on average children in the joint attention group received 28.6 sx and the symbolic play group received 34.7 sx; not a significant difference in # of sx); children in all 3 groups were also enrolled in 30 h. of ABA-based hospital early behavioral intervention	Children randomized to 1 of 3 groups: joint attention (JA), symbolic play (SP), or control group; at time of post-tx children in the JA group initiated significantly more showing and responded more to joint attention in the ESCS and more joint attention in caregiver–child play; children in the SP group showed higher levels of play in the ESCS and caregiver–child interaction and more diverse types of play during the caregiver-child interaction than the other two groups	Type 1 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, +Tx manual

Table 20.2 (continued)

Author(s) and Year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002, 2007) criteria
Kasari et al. 2008	56 ss, aged 3–4 yrs. with ASD as dx by the ADOS & ADI-R in original study; 56 ss at 6 mos. post-tx and 53 ss at 12 mos. post-tx	Assessments of joint attention (JA) skills, symbolic play (SP) skills, mother–child interactions, and language development at pre- and post-tx, and at 6 and 12 months post-tx on the MSEL, the ESCS, the Reynell Developmental Language Scales, Structured Play Assessment, and caregiver–child interaction (see Kasari et al. 2006 above for details)	See Kasari et al. 2006 above	Follow-up to Kasari et al. 2006 study above; both JA and SP groups showed significantly greater growth in expressive language over time when compared to the control group; children who begun tx at the lowest language levels showed significantly more improvement in language development in the JA group than the SP or control groups	Type 1 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, +Tx manual
Kasari et al. 2010	38 child–parent dyads; children were aged 21–36 mos. with ASD as dx by an independent clinician; parents' mean age was 34.5 yrs.; no significant differences found between parents in both groups	MSEL; child-caregiver 15 min. play interaction videotaped and coded for: (a) percentage of time in engagement states (collapsed into unengaged/other; object engagement, and joint engagement); (b) play types (functional, symbolic); and (c) frequencies of initiating and responding to joint attention; MSEL collected pre-tx and at 12-mo. follow up; parent–child play interaction was conducted at pre-tx; after 8 weeks of tx or waitlist and at 12-mo. follow up; caregivers also rated on Caregiver Quality of Involvement Scale and adherence to tx protocol	Immediate treatment (IT) group immediately received 8 weeks of tx; 3 sx/week = 24 caregiver-mediated tx sx total in a laboratory playroom setting; each sx included direct instruction, modeling, guided practice, and feedback from the interventionist; intervention focused on ten modules for teaching children joint attention and symbolic play	Child–parent dyads randomly assigned to immediate treatment (IT) group or wait-list (WL) control group; the IT group made significant improvements in amount of time in joint engagement, responsiveness to joint attention, and in the diversity of play skills when compared to the WL control group at the 8-week point; Caregivers were rated high on tx fidelity at the end of the 8 weeks of tx; tx-related gains in joint engagement, joint attention responding skills, & types of functional skills were maintained or improved for the IT group after 12 mos.	Type 1 study: +RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, +Tx manual

Table 20.2 (continued)

Author(s) and Year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002, 2007) criteria
Relationship Development Intervention (RDI)					
* *No research studies that meet Nathan and Gorman (2002, 2007) Type I, 2, 3, studies*					
Responsive Education And Prelinguistic Milieu Teaching (RPMT)/Milieu Teaching					
Hancock and Kaiser 2002	4 ss, aged 35–54 mos.; 3 male, 1 female	Collected throughout tx and follow-up: frequency of total child utterances, spontaneous child utterances, total use of targets, frequency of targets used spontaneously, # of different word roots used, and MLU; collected shortly after last tx session & last follow-up session: SICD, PPVT-R, Expressive One-Word Picture Vocabulary Test-Revised, parent satisfaction questionnaire	Therapist-implemented “enhanced milieu teaching”; single-subject, multiple baseline design; part of larger study which randomized children to different txs; children randomly assigned to a specific number of baselines; tx consisted of sessions 2x/wk for 15 min/session; clinic-based; follow-up period of 1x/mos., 15 min sessions for 6 mos.; parents did not observe sessions	All children showed positive increases for specific target language use, maintained across the 6 mos. follow-up; positive lang. effects generalized to interactions w/ mothers at home for 3/4 children; variable results across children for standardized measures	Type 2 study: −RCT, −Blind assessments, +Incl/excl criteria, +Standardized dx battery, −Comparison group, +Tx fidelity, −Tx manual
Kaiser et al. 2000	6 ss, aged 32–54 mos.; all male	Collected throughout tx and follow-up: frequency of total child utterances, spontaneous child utterances, total use of targets, frequency of targets used spontaneously, number of different word roots used, and MLU; collected shortly after last tx session and last follow-up session: SICD, PPVT-R, Expressive One-Word Picture Vocabulary Test-Revised, parent satisfaction questionnaire	Parent-implemented “enhanced milieu teaching”; single-subject, multiple baseline design; part of larger study which randomized children to different txs; children randomly assigned to a specific number of baselines; parent training consisted of sessions 2x/wk for 45 min./session; clinic-based; follow-up period of 1x/mos., 15 min. sessions for 6 mos.	Parents learned to implement procedures and maintained them over follow-up period, but at lower rates than during active tx; positive effects for use of communication targets for all children and on complexity and diversity of productive language for most children; effects generalized to home setting for 4/6 children; improvement on standardized assessments for 5/6 children	Type 2 study: −RCT,-Blind assessments, +Incl/excl criteria, +Standardized dx battery, −Comparison group, +Tx fidelity, −Tx manual

Table 20.2 (continued)

Author(s) and Year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002, 2007) criteria
Yoder and Stone 2006	36 ss, aged 21–54 mos.; 31 male, 5 female	After 6 mos. and 12 mos. (6 mos. after tx ended): free-play session w/ examiner (scored for frequency of nonimitative spoken communication acts and number of different nonimitative words spoken)	Compared "responsive education and prelinguistic milieu teaching" to PECS; 3 20-min sessions/wk for 6 mos. (1:1 w/ therapist); parent offered up to 15 h. of training; clinic-based; designed to facilitate intentional communication for the primary pragmatic functions of commenting, requesting, and turn taking	At 6 mos., PECS group more successful in increasing number of nonimitative spoken communication acts and number of different nonimitative words used; at 12 mos., exploratory analysis showed that growth rate of number of different nonimitative words faster in PECS group for children who began tx w/ high object exploration, but opposite for children who began w/ low object exploration	Type 2 study: +RCT, −Blind assessments, +Incl/excl criteria, +Standardized dx battery, +Comparison group, +Tx fidelity, +Tx manual
Responsive Teaching (RT)					
Mahoney and Perales 2003	20 ss with autism or PDD-NOS; mean age of 32 mos, with 80 % of ss under 36 mos at time of enrollment; 12 male	videotaped mother-child interactions coded with CBRS and MBRS, social-emotional functioning from ITSEA and TABS	Tx 1X/week of center-based tx and mean hour of 2.5 h/day of in-home parent-delivered tx for 8–14 mos.; tx focused on reciprocity, contingency, shared control, affect, and matching of pace during play and daily routines	Pre-post design; 80 % of mothers demonstrated significant increase in maternal responsiveness and affect. This increased responsiveness was associated with children's increased social-emotional functioning (engagement, cooperation, joint attention, and affect)	Type 3 Study: −RCT, −Blind assessments, −Incl/excl criteria, −Standardized dx battery, −Comparison group, +Tx fidelity, +Tx manual
Mahoney and Perales 2005	20 ss with PDDNOS; 20 ss with other DD; 12–54 mos with 85 % of children under 36 mos at time of enrollment; 62 % males	Developmental Rainbow, TBPA, videotaped mother–child interactions coded with CBRS and MBRS, social-emotional functioning from ITSEA and TABS	1 h/week of parent–child sx at home or at center with early intervention specialist for 1 year; approx. 15 h/wk of parent-delivered tx (parent report); tx focused on cognitive, communication, and social-emotional functioning influenced by parental responsiveness	Pre-post design; significant increases in maternal responsiveness; significant increases in children's communication, cognitive, and social-emotional functioning; PDDNOS group showed greater gains in development; child outcomes were related to maternal responsiveness	Type 3 Study: −RCT, −Blind assessments, −Incl/exl criteria, −Standardized dx battery, −Comparison group; +Tx fidelity, +Tx manual

Table 20.2 (continued)

Author(s) and Year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002, 2007) criteria
Social Communication, Emotional Regulation, and Transactional Support (SCERTS)					
Wetherby and Woods 2006 (preliminary study: Early Social Interaction Project)	35 ss total: 17 ss; 12–24 mos. of age; with significant red flags for ASD and a provisional clinical diagnosis of ASD; 18 ss in contrast group; 25–36 mos. with "suspected" ASD diagnosis	MSEL; VABS; ADOS; video taped behavior sample coded with CSBS DP	Two home visits per week for 1 year by trained interventionists with focus on increasing communication during daily routines & participation in parent-child FIRST WORDS playgroup for 9 weeks during tx year	Quasi-experimental, one-group pretest-posttest design with a no-treatment contrast group at post only; significant increases in 11 of 13 social communication measures of the CSBS DP, including initiating and responding to joint attention; at post tx group and contrast group were comparable on communicative means and play, but contrast group had significantly poorer performance on all other social communication measures	Type 3 Study: −RCT, +Blind assessments, +Incl/excl criteria, +Standardized dx battery, +/-Comparison group (only posttest), +Tx fidelity, −Tx manual
Treatment and Education for Autistic And Related Communication Handicapped Children (TEACCH)					
Short 1984	15 ss; 2.3–7.5 yrs (mean 4.7 yrs.); 12 boys and 3 girls; all met Rutter's 4 criteria (1978) for diagnosis of autism	(1) Behavioral observation coding for parental and child behavior; (2) semi-structured maternal interview on family stress in relation to child w/ autism; (3) questionnaire on effects of child problems on family; (4) parental questionnaire on effects of tx	Tx group compared to wait period control; tx = 4 mos. 29 days; wait period = 1 mo 29 days; tx = TEACCH 6-8 sx of 60–90 min/each	Parental guidance and appropriate child behavior were significantly greater during tx period than during wait period; reductions of inappropriate child behavior and family stress were not significantly different in tx period than wait period	Type 2 Study: −RCT, +Blind assessments, +/-Incl/excl criteria, -Standardized dx battery, +/−Comparison group, −Tx fidelity, −Tx manual

Table 20.2 (continued)

Author(s) and Year	Sample	Outcome measures	Treatment procedures	Findings	Nathan and Gorman (2002, 2007) criteria
Ozonoff and Cathcart 1998	22 ss; 2–6 yrs of age; 18 boys; 4 girls; all diagnosed with autism	PEP-R; CARS	Tx group = therapist & parent designed tx plan; 10 weeks of 1 h/TEACCH-based home program services with trained graduate students + 1 h clinic visit/week at beginning & gradual decrease to 1 sx/2–3weeks toward end; 1/2 h of tx by parents/day; control group = community tx as usual	Tx group improved significantly more than control group on PEP-R subtests of imitation, fine motor, gross motor, and nonverbal conceptual skills, and overall PEP-R scores	Type 2 Study: − RCT, − Blind assessments, − Incl/excl criteria, − Standardized dx battery, + Comparison group, − Tx fidelity, − Tx manual

#=number, *mos* months, *wk* week, *yr* year, *bx* behavior, *dx* diagnosis, *hx* history, h hour, s second *tx* treatment, *sx* session, *sig*. significant, *ss* subjects, *ASD* Autism Spectrum Disorder, *PDD-NOS* Pervasive Developmental Disorder-Not Otherwise Specified, + present in the study, – absent in the study, *incl/excl criteria* inclusion/exclusion criteria, *A/M* assess and monitor HMTW Hanen's More than Words, and PECS Picture Exchange Communication System and DD Developmental Delay, min minute and RCT randomized control trial, FEAS Functional Emotional Assessment Scale, FEDQ Functional Emotional Developmental Questionnaire and SICD Sequenced Inventory of Communication Development

ADI Autism Diagnostic Interview, *ADOS* Autism Diagnostic Observation Scale, *CARS* Childhood Autism Rating Scale, *CBRS* Child Behavior Rating Scale, *CSBS DP* Communication and Symbolic Behavior Scales Developmental Profile, *ESCS* Early Social-Communication Scales, *ISCQ* Infant Social-Communication Questionnaire, *ITSEA* Infant Toddler Social Emotional Assessment, *M-CHAT* Modified Checklist for Autism in Toddlers, *MBRS* Material Behavior Rating Scale, *MCDI* MacArthur-Bates Communicative Developmental Inventory, *MLU* mean length of utterance, *MSEL* Mullen Scales of Early Learning, *PEP-R* Psychoeducation Profile Revised, *PDD-ST-II* Pervasive Developmental Disorders Screening Test-II,*RBS* Repetitive Behavior Scale, *TABS* Temperament and Atypical Behavior Scale, *TBPA* Transdisciplinary Play Based Assessment, *VABS* Vineland Adaptive Behavior Scale of the main features of each study reviewed, including the sample, outcome measures, treatment procedure, findings, and Nathan and Gorman (2002, 2007) study type representing methodological rigor.

Following Table 20.2 is a brief description of the main tenants of each treatment approach, including a summary of the developmental components of each approach. A review of the selected efficacy studies that met the search criteria for each approach follows. Next is an overall summary of the empirical evidence for developmental treatment approaches for young children with autism, including a discussion of study limitations. The chapter concludes with recommendations for the future, both in terms of additional efficacy and effectiveness studies, as well as the development or modification of treatment approaches to meet the developmental needs of younger children with autism.

Developmental Approaches

Denver Model and Early Start Denver Model (ESDM)

The Denver Model, created in the 1980s at the University of Colorado Health Sciences Center, is a developmental approach for preschool education for children from 2 to 5 years of age with autism (Rogers et al. 1986; Rogers 2005). The Denver Model is administered to small groups of young children with autism in a classroom setting for 4–5 h per day, 12 months a year. The core features of the Denver Model include: (a) an interdisciplinary team that implements a developmental curriculum addressing all domains for each child's individual needs; (b) a focus on interpersonal interactions and engagement; (c) a focus on reciprocal, functional and spontaneous use of imitation, facial expressions, and objects; (d) an emphasis on verbal and nonverbal communication; (e) a focus on the cognitive aspects of play; and (f) the importance of developing partnership with parents (Dawson and Rogers 2010, p. 15). The Denver Model strongly emphasizes social relationships by using positive affect in social interactions as a motivator for children to pay attention to others and engage in social interactions, by assigning each child to a primary teacher, by fostering peer relationships, and by modeling and prompting social behaviors (Rogers et al. 2001). Families are integral to the Denver Model programs. Parents of children attending the Denver Model programs are encouraged to observe and participate in their children's classroom. In addition, parents are given a chance to discuss their child's development or other issues related to parenting a child with ASD during their weekly one-on-one consultation with a child psychologist or psychiatrist or during monthly parent support group meetings with other families in the program.

The Early Start Denver Model (ESDM) is a comprehensive early developmental intervention for children as young as 12 months of age with ASD. ESDM was designed by Rogers and Dawson (2010), and is based upon the Denver Model. At the heart of ESDM are the empirical knowledge base of infant-toddler learning and development and the effects of early autism. ESDM is typically provided in the home by trained therapists and parents during natural play and daily routines. However, current studies are examining group delivery in preschools and childcare centers. The aim of ESDM is to increase the rate of development in all domains for children with ASD and to simultaneously decrease the symptoms of autism. In particular, this intervention focuses on boosting children's social-emotional, cognitive, and language skills, as development in these domains is particularly affected by autism. ESDM also uses a data-based approach and empirically supported teaching practices that have been found to be effective from research in ABA. ESDM fuses behavioral, relationship-based, developmental, and play-based approaches into an integrated whole that is individualized and standardized. Teaching objectives are based on the *Early Start Denver Model Curriculum Checklist*, a play-based assessment tool that lists behaviors in each developmental domain in the order in which they occur in typical development. In ESDM, a primary therapist, supported by an interdisciplinary team comprised of occupational therapists, speech pathologists, child psychologists, behavior analysts, physicians, and special educators, assesses the child and identifies developmental objectives to target during intervention. Parents learn to deliver ESDM by using the play-based interactive approach to embed learning opportunities into their daily routines with their children. In intensive delivery of ESDM, each child receives direct intervention one-on-one from members of a team of trained ESDM interventionists, as well as from his or her parents.

Both the Denver Model and the ESDM meet all five criteria of a developmental approach to treating young children with autism. The creators of these approaches self-identify the treatments as "developmental." Treatments are based on a typical developmental framework, follow the principles of developmental science, are delivered in the context of relationships, are child-centered and play based. Both approaches are comprehensive. Whereas the Denver Model is administered primarily in a therapeutic preschool setting by trained teachers and specialists, the ESDM is administered in the clinic and at home by trained intervention therapists guided by an interdisciplinary team. Both approaches include a parent training component with an expectation that parents use the techniques with their children during daily play activities and caregiving routines at home.

There are a handful of studies published in peer-reviewed journals that report the efficacy of the Denver Model before it was officially called by this name (Rogers et al. 1986, 1987; Rogers and Lewis 1989; Rogers and DiLalla 1991). Consequently, the systematic search criteria of this literature review resulted in only one efficacy study of the Denver Model, as described in Table 20.2. In 2006, Rogers and colleagues reported a Type 2 study using a single-subject study design that included the randomization of a sample of ten nonverbal male subjects from 20–65 months of age to either the Denver Model treatment group or the PROMPT treatment group, which is a neurodevelopmental approach for speech production disorders. Each group received 12 weekly 1-hour therapy sessions and 1 hour of parent-delivered intervention at home each day. After the 12 weeks of treatment, there were no significant differences in the acquired language skills of each group, as eight of the ten children used five or more new words spontaneously. In addition to comparing two different treatment methods, this study also considered the profiles of the children that responded best to both treatments; these "best responders" had mild to moderate symptoms of autism, and better motor imitation and joint attention skills when compared to children who did not respond as well to either treatment method.

Two studies investigating the efficacy of ESDM are described in Table 20.2, one of which is a Type 2 study because it had single-subject design and one that is a Type 1 randomized control trial (Nathan and Gorman 2002, 2007).

The Type 2 study of the efficacy of ESDM (Vismara et al. 2009) included a sample of eight subjects ranging from 10 to 36 months of age with diagnoses of ASD at some point during the treatment. Each parent–child dyad received 12 weeks of one-on-one coaching using the ESDM model. Parents achieved ESDM treatment fidelity by the sixth treatment session and children demonstrated positive changes in social communication behaviors, such as imitation and spontaneous verbal utterances. Together, these two single-subject studies demonstrate that parents can learn to use ESDM when interacting with their young children over the course of 12 parent-coaching sessions. Children in these studies demonstrated associated increases in social communicative behaviors during parent–child play over the course of the parent training; however, because of the study designs, causal relationships between implementation of ESDM and child outcomes cannot be assumed.

The final ESDM study included in this review is a Type 1 study, a randomized, controlled trial that evaluated the efficacy of intensive ESDM treatment (Dawson et al. 2010). Forty-eight children diagnosed with ASD between 18 and 30 months of age were randomly assigned to either the ESDM group or the community treatment group. The children in the ESDM group received intervention by trained therapists within 2-hour sessions occurring twice per day for 5 days per week for 2 years (on average, ESDM children received 15.2 hours of ESDM and 5.2 hour of additional community therapy per week). In addition, parents were trained and asked to use ESDM strategies during daily activities (reporting on average 16 hours per week). The control group reported receiving an average of 9.1 hours per week of individual therapy and an average of 9.3 hours per week of group intervention (e.g., inclusive preschool programs). At the end of the 2-year period, children in the ESDM group showed significant improvements in IQ, language, and adaptive behavior when compared to children who had received treatment from the community, even though the groups differed little on the average number of hours of intervention received over the 2-year period. Additionally, children who received ESDM were significantly more likely to have improved diagnostic status than the children in the community treatment group.

Developmental Individual-Differences, Relationship-Based (DIR/Floortime) Model

The Developmental Individual-Difference, Relationship-Based (DIR/Floortime) Model, created by Greenspan and Wieder (Wieder and Greenspan 2001), is a comprehensive intervention for infants, toddlers, and preschoolers with ASD. This developmental intervention aims to "reestablish the developmental sequence that went awry" (Greenspan and Wieder 2007, p. 189). It considers each child's current developmental level of emotional functioning, biologically based individual differences in sensory processing, relationships with parents and caregivers, as well as the child's context of family and culture. The primary goal of this approach is to facilitate a child's sense of self as an intentional being in the context of relationships and to build the child's cognitive, language, and social capacities. This model includes a nine-step formal assessment process, including consultation with a multidisciplinary team and the child's parents, to determine how biological, maturational, environmental, and social factors contribute to a child's competencies and symptoms. In particular, the DIR/Floortime model is designed to help a child progress through six functional emotional developmental levels (FEDLs). A child's FEDL refers to how he/she is able to integrate all of his/her capacities (motor, cognitive, language, spatial, and sensory) to carry out emotionally meaningful goals (Greenspan and Wieder 2007). The six FEDLs, from simplest to most complex, are as follows: (1) sharing attention and regulation; (2) engagement and relating; (3) two-way intentional affective signaling and communication; (4) long chains of co-regulated emotional signaling and shared social problem solving; (5) creating representations or ideas; and (6) building bridges between ideas, including logical thinking (Greenspan and Wieder 2006).

The cornerstone of the DIR intervention is Floortime sessions, which are unstructured play sessions in which the adult (therapist, educator, or parent) follows the child's lead in interactions with the goal of building warm, trusting relationships that encourage shared attention, interaction, and communication; these relationships become the context for the child to progress through the six FEDLs. Oftentimes, the therapist works with the child's parents and educators to help them to develop the skills to facilitate Floortime play sessions. Comprehensive DIR/Floortime interventions include additional activities and therapies (e.g., speech, sensory integration, occupational or physical therapies, peer play dates, biomedical interventions, nutritional counseling, and family consultation or counseling), which are selected to meet each child's developmental profile and each family's needs.

The DIR/Floortime Model contains all five components of a developmental approach to treating young children with autism. The DIR/Floortime model focuses on the development of social and emotional functioning in the context of close relationships. Although this approach focuses on social-emotional development, this method was designed to be comprehensive, as it also aims to increase the integration of a child's motor, cognitive, language, spatial, and sensory capacities. Therapists work together with parents either in the clinic, at home, or in the child's educational setting so that parents and teachers learn strategies to help the child function at his/her highest developmental level.

Three studies on the efficacy of the DIR/Floortime Model are described in Table 20.2. The first study reviewed included a unique design by

Hilton and Seal (2007) in which 2-year-old twin brothers with ASD were each randomly assigned to DIR treatment or ABA treatment. After approximately 17 sessions, the behavioral data coded with the Communication and Symbolic Behavior Scales (CSBS) revealed that there were increases in the number and duration of crying episodes in the ABA child but not in the DIR child. There was also a slight gain in communication composite score for the ABA child and slight loss for the DIR child. This study is considered a Type 3 study (Nathan and Gorman 2002, 2007).

The second DIR/Floortime Model efficacy study was conducted by Solomon et al. (2007). This study examined the efficacy of the PLAY Project Home Consultation Project, in which the parents of the 68 subjects (ranging from 18 months to 6 years of age at the time of their diagnosis) were trained with the DIR/Floortime Model. Parents were asked to implement the model for 15 hours per week for 1 year. Pre- and post parent–child interactions were videotaped and coded by blind raters using the Functional Emotional Assessment Scale (FEAS). Although parents' ratings did not change from pre to post, approximately 45 % of the children made "good" to "very good" functional developmental progress, as defined by the FEAS. Although the results of this pilot study are promising, this study did not include a control group and had significant methodological limitations, so it is rated in this review as a Type 3 study (Nathan and Gorman 2002, 2007).

The third study reviewed on the efficacy of the DIR/Floortime Model is a Type 1 study of a randomized control trial of 32 subjects from 2 to 6 years of age (Pajareya and Nopmaneejumruslers 2011). Children were randomly assigned to a preschool as usual group or to a group receiving both preschool and a home-based intervention based on the DIR/Floortime Model. Parents who received the DIR/Floortime home-based intervention implemented this model for an average of 15.2 hour per week for 3 months. After 3 months, children were assessed with the FEAS, the Childhood Autism Rating Scale, and the Functional Emotional Questionnaires. Overall, children who received the additional home-based DIR/Floortime interventions demonstrated significant gains over the children who did not receive this added component. Because this is a Type 1 study, the evidence of treatment efficacy for the DIR/Floortime Model demonstrated by this study is stronger than the previous two studies reviewed. Additional randomized control trials that compare the DIR/Floortime Model to other developmental treatment models would strengthen the evidence base for this approach.

Hanen's More than Words

Hanen's More than Words is a parent training program that is designed to teach parents strategies to increase children's communication via enhancing parents' responsivity to children's attention and communication attempts. These strategies are designed to be used during everyday routines with young children diagnosed with autism, and are focused on helping children reach four goals: improved two-way interaction, more mature and conventional ways of communicating, better skills in communicating for social purposes, and improved understanding of language. Intervention is aimed at improving parent–child interaction, and focuses on teaching parents how to structure everyday routines in a manner that is sensitive to the child's developmental level, how to provide appropriate verbal and nonverbal responses to children's communication, and how to provide multiple opportunities for children to respond. The intervention involves eight group sessions with parents only, as well as three in-home sessions with parents and children (Carter et al. 2011; Sussman 1999).

More than Words contains all five of the components of a developmental approach to treating children with ASD. It takes children's developmental level and principles of developmental science into account and is relationship based, child-centered, and play based. It is targeted, focusing on communication and social interaction, and is carried out by parents in naturalistic settings.

There are three studies investigating More than Words described in Table 20.2, two of which are rated as Type 2 studies and one which is rated as a Type 1 study (Nathan and Gorman 2002, 2007). Overall, studies show mixed results in terms of child outcome due to the intervention. For example, Carter et al. (2011) conducted a randomized control trial investigating More than Words in a sample of 62 children with autism, aged 15–24 months. Children were assigned to either the experimental treatment or to a control group consisting of community treatment. Researchers found no main effects of More than Words on parents' responsivity several months after enrollment, as measured by a partial interval coding system of parent–child free play videos, although they did find medium effect sizes. In addition, there were no main effects of treatment on children's communication. The intervention did, however, facilitate communication in children who had exhibited low levels of object interest at the beginning of treatment. Similarly, in a single-subject design conducted by Prelock et al. (2011) involving four participants aged 37–69 months, three of the four children showed improvements in social and symbolic communicative acts and vocabulary, but not on a standardized developmental test (Mullen Scales of Early Learning; Mullen 1989). McConachie et al. (2005) carried out a randomized control trial in which 51 subjects received a 3-month course of weekly More than Words sessions along with three home visits. The treatment group was compared to a wait-list control group. Children who received the More than Words treatment demonstrated significantly larger vocabulary sizes than those in the wait-list control, even when considering the child's scores at time of recruitment, the diagnostic group, and the interval between assessments. Further research investigating More than Words may help to clarify the mixed outcome results found thus far.

Joint Attention Mediated Learning (JAML)

There are two "branded" developmental interventions for autism in young children that target improvement of a child's skills in initiating and responding to joint attention—Joint Attention Mediated Learning (JAML) and Joint Attention Symbolic Play Engagement and Regulation (JASPER, see next section), since deficits in joint attention are unique to autism. Both of these interventions target building this skill, as joint attention is a developmental precursor to social learning, and therefore has a cascading effect on many areas of a child's development (Schertz and Odom 2007).

JAML (Schertz 2005), is a manualized treatment approach focused on the developmental foundations of joint attention. The five parent-mediated learning principles include: (1) focusing—helping the child to learn by focusing his/her attention; (2) giving meaning—helping the child to understand the meaning of objects or activities by expressing emotion; (3) expanding—helping the child expand his/her understanding by labeling, pointing out salient features or events, and making connections; (4) encouraging—encouraging the child's learning by creating optimal and achievable challenges and by acknowledging his/her success; (5) organizing and planning —helping the child learn by structuring activities and daily routines into predictable sequences of events. In addition, JAML suggests strategies for parents to use to help their children develop social-communication skills in four areas: (1) focusing on faces, (2) turn-taking, (3) responding to joint attention, and (4) initiating joint attention.

JAML meets all five requirements of a developmental approach to treating young children with ASD. The developmental sequence of joint attention is based on typical development and is supported by developmental theory and research. It is relationship based, as it is a model that focuses on learning in the context of the parent–child relationship. Likewise, it is child-centered and play based, as parents are coached to follow their child's lead in play activities by joining their child's play instead of introducing a parent-initiated play theme for the child to follow. As mentioned earlier, JAML is a targeted approach focused on increasing the child's joint attention abilities, which have a cascading effect on social learning in all other domains. The JAML approach is primarily a parent-coaching model and activities are to be conducted in naturalistic settings, such as the child's home.

One Type 2 study on the JAML approach is reported in Table 20.2. Schertz and Odom (2007) explored the effectiveness of the JAML approach through a single-subject multiple baseline design. The sample included three subjects diagnosed with ASD between 20 and 28 months of age. Parent–child dyads were videotaped for 10 minute play sessions during a baseline period and during each week of treatment. Videos were coded for the number of 10-second intervals in which the child was engaged in one or more of the four joint attention behaviors: (1) focusing on faces, (2) turn taking, (3) responding to joint attention, and (4) initiating joint attention. Parent–child dyads received between 11 and 16 in home parent-coaching sessions over a 9–26 week period. Each of the three toddlers surpassed baseline performance levels of displays of all four joint attention behaviors during parent–child play in comparison to baseline levels. The addition of some Type 1 studies on the efficacy of this approach would add to the evidence base for JAML.

Joint Attention and Symbolic Play Engagement Regulation (JASPER)

Whereas JAML focuses primarily on joint attention, JASPER focuses on joint attention and also includes a focus on developing the symbolic play skills, another known deficit of young children with ASD. JASPER is a targeted intervention on these two developmental skills, which impact children's social and communication development. The JASPER approach was developed by Connie Kasari and colleagues at the University of California Los Angeles, and has evolved alongside 10 years of studies on using this approach with children under the age of 3 years. Although JASPER was originally administered by trained interventionist working directly with the children in a laboratory setting, more recent studies include a parent-mediated intervention. JASPER incorporates behaviorist principles in conjunction with developmentally informed practices. The treatment is individualized to meet the developmental needs of each child, and the intervention is structured around the typical developmental sequences of joint attention and symbolic play (Kasari et al. 2010). Consequently, intervention goals for each child stem from the child's initial developmental assessments. The parent-mediated model of JASPER is organized around ten learning modules: (1) setting up the environment; (2) allowing the child to initiate an activity; (3) playing within established routines; (4) facilitating and maintaining states; (5) scaffolding and engagement state; (6) facilitating joint engagement; (7) allowing the child to initiate communication; (8) recognizing and responding to the child's joint attention skills; (9) imitating and expanding language; and (10) generalizing skills to other routines. JASPER is typically administered in a laboratory setting by a trained interventionist, with the goal of skill generalization to the child's natural environment.

JASPER meets all five components of a developmental approach to treating young children with autism. The creators of these approaches self-identify the treatments as "developmental." JASPER also uses behaviorist principles in conjunction with principles from developmental science. Treatments are based on typical developmental sequences for joint attention and symbolic play, and are delivered in the context of relationships with an interventionist or the parent. JASPER is a child-centered and play-based model. As previously mentioned, this approach is a targeted intervention, focusing on joint attention and/or symbolic play skills. JASPER can be administered by trained interventionists in a laboratory setting or through parent-mediated intervention with a focus on generalizing the skills to the child's natural environment.

There are three studies investigating the JASPER approach described in Table 20.2, all of which are rated as Type 1 studies (Nathan and Gorman 2002, 2007). Kasari et al. (2006) conducted a randomized controlled intervention study of joint attention intervention, symbolic play intervention, and a control group (It is important to note that the Kasari et al. 2008 study is a follow-up study of the sample from the Kasari et al. 2006 study). The sample consisted of 58 children diagnosed with autism between 3 and 4 years of age. All 58 children were also enrolled in 30 hour a week of an ABA early behavioral intervention in a hospital setting. The 58 children were randomly assigned to a joint attention group, a symbolic playgroup, or a control group. Joint attention and symbolic play interventions were conducted in one-on-one therapist-child sessions for 30 min per day for 5 to 6 weeks. Pre- and post-intervention samples of child's joint attention skills, play skills, and parent–child interactions were collected. At post-intervention, children in the joint attention group initiated more showing behaviors and responded to joint attention bids from communication partner significantly more than children in the symbolic playgroup and the control group. In addition, children in the symbolic playgroup demonstrated more diverse types of symbolic play and higher play levels in both the structured play assessment and the mother–child interaction than children in either of the other groups. This study demonstrates the specificity of intervention targets (joint attention or symbolic play). In 2008, Kasari and colleagues followed up this sample to determine if there were differences between groups in language development 12 months after the end of treatment. This follow-up study found that children in both the joint attention group and the symbolic playgroup had showed significantly higher levels of language development a year after treatment ended than the control group. In addition, children who had the lowest language levels at the beginning of treatment showed greater gains in language development if they were randomized to the joint attention group.

The third study on the JASPER approach reported in this review is also a Type 1 randomized control study. This study differs from the first two studies in that the intervention consisted of a parent-mediated joint engagement intervention (Kasari et al. 2010). The 38 child–parent dyads were randomly assigned to an immediate treatment (IT) group or a wait-list (WL) control group. Children in the study were between 21 and 36 months of age and all had a diagnosis of ASD. Children in the IT group immediately received 8 weeks of treatment occurring three times per week in a laboratory playroom setting. During treatment sessions, the interventionists covered topics focused on increasing children's joint attention and symbolic play and coached the parent through direct instruction, modeling, guided practice, and feedback. All parent–child dyads were videotaped during a play interaction at time of enrollment, at the 8-week mark, and again after 12 months. Children in the IT group made significant improvements in the amount of time they spent in joint engagement, responsiveness to joint attention, and in the diversity of their play skills when compared to the WL group after the 8 weeks of treatment. In addition, parents in the IT group displayed high fidelity to the JASPER treatment approach. One year after the end of treatment, the IT group's gains were maintained or improved when compared to the WL group, indicating that this short-term, parent-delivered intervention can have lasting effects on children's joint attention and play skills. The rigorous methods in these three Type 1 studies on the efficacy of the JASPER approach in improving joint attention, play skills, and language in young children with ASD provide promise for this approach, however, replication studies with larger sample size would strengthen these findings.

Relationship Development Intervention (RDI)

Relationship Development Intervention (RDI) is a parent-delivered intervention for children diagnosed with ASD. It attempts to address the difficulties in perception, cognition, and emotion that children with ASD often face (Gutstein et al. 2007). More specifically, the goal of RDI is to improve the child's social skills, adaptability, and self-awareness. The six objectives of the intervention are to improve: (1) emotional referencing, (2) social coordination, (3) declarative language, (4) flexible thinking, (5) relational information processing, and (6) foresight and hindsight (Autism Speaks 2011a). The intervention relies heavily upon the relationship between parents and their children, and utilizes a guided participation approach through which parents learn to perceive and scaffold opportunities for their child to respond in more flexible and thoughtful ways and to engage more successful social exchanges. The comprehensive intervention is delivered in a naturalistic setting, as parents are trained to create and capitalize upon teaching opportunities in the child's everyday environment and activities (Gutstein and Sheely 2002).

RDI contains four of the five criteria for a developmental approach to treating children with ASD. The treatment is heavily dependent upon the relationship between parents and children—in fact, this component is central to the intervention's delivery. Other adults do not work directly with the children in this intervention; instead, they serve only to train parents in the theory, principles, and components of the intervention, as well as to help parents develop the program and discuss children's treatment goals. RDI does follow the sequence of typical development, and is conducted in a naturalistic environment.

There are no research studies investigating RDI that meet our search criteria. While one study emerged in our electronic searches (Gutstein et al. 2007), the mean age of subjects within the study was over 5 years. Further research investigating RDI for toddlers and preschoolers with ASD is warranted.

Responsive Education and Prelinguistic Milieu Teaching (RPMT)/Milieu Teaching

RPMT/milieu teaching is a naturalistic behavioral intervention that uses specific behavioral teaching strategies such as prompting, shaping, chaining, and reinforcement to teach language skills to young children with autism (Schreibman and Ingersoll 2011). The intervention capitalizes upon a child's intention to communicate and systematically provides both models of language and communication as well as naturally related social consequences for language and communication attempts. Like Pivotal Response Training (PRT), RPMT/milieu teaching follows the child's lead and focuses on his moment-to-moment interests in order to increase motivation and opportunities for communicative learning. A typical milieu teaching procedure begins with the child's verbal or nonverbal request, after which the parent or therapist follows a specific sequence of prompts to help elicit language (e.g., modeling). Following the eliciting prompts, corrective prompts are used as needed, and then the parent or therapist reinforces the child's attempt by providing positive feedback and accessing the child's requested object while providing expansion of the child's utterance (Kaiser et al. 2000).

RPMT/milieu teaching contains four of the five components of a developmental approach to treating children with ASD. It applies principles of developmental science to teach language to children at a level appropriate to them. In addition, it is child-centered and play based, focusing heavily on following a child's lead in order to help elicit naturally occurring communicative attempts. Although it is a targeted intervention, focusing on communication and language, both therapists and parents can provide the intervention and it can be easily applied in a naturalistic environment.

Three studies investigating RPMT/milieu teaching are described in Table 20.2, all of which are rated as Type 2 studies (Nathan and Gorman 2002, 2007). Although, in general, we excluded studies investigating mixed interventions (e.g., PRT mixed with Picture Exchange Communication System (PECS)), we included studies investigating enhanced and modified versions of pure milieu teaching. Of the three studies investigating milieu teaching, two investigate enhanced milieu teaching, which incorporates environmental arrangement to promote child engagement with activities and communication partners, as well as responsive interaction techniques to build social, conversational interaction and to model new language forms, into pure milieu teaching procedures to prompt, model, and provide consequences for the use of new language forms. Both of these are single-subject, multiple baseline studies, involving four and six participants, respectively (Hancock and Kaiser 2002; Kaiser et al. 2000). Hancock and Kaiser (2002) investigated therapist-delivered enhanced milieu teaching provided to three males and one female aged 35–54 months in a clinic for 24 15-min sessions, and found that although there were variable results across children for standardized measures, all children showed positive increases for specific target language use. These positive language effects generalized to interactions with mothers at home, although mothers did not observe treatment sessions, for three of the four participants. In contrast, Kaiser et al. (2000) investigated parent-implemented enhanced milieu teaching for six males aged 32–54 months. Parents were trained in 24 45-min sessions, and researchers found positive effects for use of communication targets for all children and for complexity and diversity of produced language for most children, as well as generalized effects to the home environment for four of the six participants and improvements on standardized measures for five of the six participants.

The third study investigating RPMT/milieu teaching utilized responsive education and prelinguistic milieu teaching, which mirrors pure milieu language teaching but focuses instead on teaching children prelinguistic goals, such as the use of gestures, nonword vocal use, and gaze use (Yoder and Stone 2006). This randomized control trial included 36 participants aged 21–54 months and compared the use of RPMT to PECS, providing treatment for a maximum of 24 total hours across a 6-month period. After 6 months, participants in the PECS group were more successful in increasing the number of nonimitative spoken communicative acts and the number of different nonimitative words used. After 12 months, at follow-up, exploratory analysis indicated that the growth rate of the number of words was faster in the PECS group for children who began treatment with high object exploration, but opposite for children who began with low object exploration (Yoder and Stone 2006).

Overall, research investigating RPMT/milieu teaching is scarce. Much of the existing research relies on single-subject designs, and the one study utilizing a randomized control design yielded mixed results. Further research investigating RPMT/milieu teaching for toddlers with ASD, especially that involving additional subjects and control groups, is warranted.

Responsive Teaching (RT)

The responsive teaching (RT) curriculum, created by Mahoney and MacDonald (2005), is a parent-mediated developmental intervention. The RT curriculum focuses on teaching parents to use responsive interaction strategies to address their children's individualized developmental needs in the domains of cognition, communication, and social-emotional functioning (Mahoney and Perales 2003). There are 19 predefined pivotal intervention objectives designed to target these developmental domains. Each of these objectives was chosen because there is empirical support that maternal responsiveness affects these child behaviors, which in turn impact development in each domain. The model is primarily a parent-coaching model, with a series of intervention topics that cover 70 RT Strategies based on the following dimensions of responsive interaction: reciprocity, contingency, shared control, affect, and match (Mahoney and MacDonald 2005). In addition, RT intervention topics help parents and teachers understand how each of the pivotal intervention topics contributes to their child's development (Mahoney and MacDonald 2005). These RT Strategies are to be incorporated into parents' or teachers' daily routines with the children in their care in order to maximize each child's developmental potential. The RT model is thoroughly described and outlined in a treatment manual (Mahoney and MacDonald 2005).

The RT curriculum contains all five criteria of a developmental approach to treating young children with ASD. It is based on sequences of typical child development, is supported by developmental theory and research, and is relationship based, child-centered, and play based. Although this model is based on strengthening the 19 pivotal intervention objectives, this approach is considered to be comprehensive, as together these objectives target the main developmental domains. The RT approach is focused on parent coaching in naturalistic settings.

There are only two studies on the efficacy of the RT that meet our search criteria, both of which are rated as Type 3 studies because they have pre-post designs (Nathan and Gorman 2002, 2007). Both of these studies were conducted by Mahoney and Perales. In 2003, Mahoney and Perales conducted a study on the effects of RT intervention on the social-emotional functioning of a convenience sample of 20 children with ASD who received a mean of 31 h of parent–child intervention over the course of a year. From pre- to post-intervention, mothers demonstrated significant improvements in responsiveness, and these changes in maternal responsiveness accounted for 25 % of the variance in changes in the social-emotional functioning of the children.

The second study (Mahoney and Perales 2005) was conducted with a sample of 50 parent–child dyads. Twenty of the children had pervasive developmental disorders (PDD) and 30 had other developmental disabilities (DD). Parent–child dyads received weekly RT sessions for approximately 1 year. Children's social-emotional functioning and overall development and parents' level of responsivity before and after receiving the RT intervention were compared. Overall, parents in both groups showed significant increases in their levels of responsiveness as measured in parent–child play interactions. Both groups of children made significant developmental progress, with children in the PDD group showing significantly greater developmental progress than children in the DD group, although this was related to the fact that parents in the PDD group demonstrated greater positive changes in responsiveness from pre- to post-intervention than did parents in the DD group.

Because both of these studies are based on a quasi-experimental pre-post design, the evidence base for the efficacy of RT would be strengthened by future research that meets the Nathan and Gorman criteria for a Type 1 study.

Social Communication, Emotional Regulation, and Transactional Support (SCERTS)

The SCERTS model of ASD intervention aims to enhance communication and social-emotional abilities of children through a comprehensive curriculum supported by a multidisciplinary team (Prizant et al. 2003). This approach targets the following core developmental challenges faced by children with ASD: social communication, emotional regulation, and transactional support. Transactional support is a unique component of the SCERTS model and refers to the learning supports that professionals provide to a child across daily activities in their natural settings, as well as to the interpersonal supports provided to the child's family, teachers, and community members to maximize the child's ability to be successful in all contexts and with all interactional partners (Prizant et al. 2006a). The SCERTS manual focuses primarily on implementing this model with preschool-age children and with children in the primary grades; however, this is a life-span model. Children supported by SCERTS often attend inclusive preschool settings where they can learn with and from typically developing children in a naturalistic educational context. The teaching strategies in this model aim to directly target skills during naturally occurring, everyday routines so that learning happens both in meaningful and purposeful activities and so that children are motivated to initiate communication in these activities. In addition, SCERTS includes educational and emotional supports for families, as well as support for teamwork within the child's professional team (Autism Speaks 2011b). The creators of SCERTS identify its strength as "…the integration of understanding a child in the context of his or her family and daily activities and the transactional impact of people and learning supports that become critical influences on the child's development in everyday experiences" (Prizant et al. 2006b, pp. 1–2).

SCERTS contains all five components of a developmental treatment approach for young children with autism. The model's treatment goals and teaching strategies are derived from research and literature on the development of children with and without disabilities. In addition, SCERTS has a strong focus on learning in the context of relationships with familiar caregivers to enhance social interactions and regulation. The teaching in SCERTS is child-centered as it follows the child's focus of attention, and is also play based.

In addition to these five developmental components, the SCERTS Model is comprehensive, as it focuses on all areas of child development, specifically concentrating on the developmental challenges of children with ASD. Children being treated via SCERTS usually attend an inclusive preschool setting. In addition, parents are taught to administer the model during daily interactions at home and in the community.

To date, there are no treatment studies on SCERTS that meet the search criteria for this review; research investigating the efficacy of SCERTS for young children with ASD is needed. However, the SCERTS model shares many of the same theoretical and pragmatic foundations as the Early Social Interaction (ESI) Project by Woods and Wetherby (2003), as the ESI Project informed the development of the SCERTS model. The ESI Project incorporates the recommendations of the NRC (2001) for toddlers with ASD by focusing on a parent-implemented model that embeds naturalistic teaching strategies in everyday routines.

In a Type 3 study of the preliminary effects of the ESI Project, Wetherby and Woods (2006) aimed to evaluate the effects of an ESI parent-implemented intervention on social communication outcomes. This preliminary study had a quasi-experimental pre-post design with a contrast group at time of post only. The treatment group consisted of 17 toddlers who were identified as having significant red flags for ASD and were consequently given a provisional clinical diagnosis of ASD before their second birthday. These 17 parent–toddler dyads received a year of treatment consisting of two home visits per week for 12 months in which a trained interventionist worked with parents to meet each child's individual needs within typical daily routines in the natural environment. In addition, all 17 of these children attended 9 weeks of the FIRST WORDS Project parent–child playgroup. The treatment group displayed significant increases in 11 of 13 social communication measures of the Communication and Symbolic Behavior Scales Developmental Profile (CSBS DP), including initiating and responding to joint attention. A contrast group consisting of 18 children between the ages of 2 and 3 years who were suspected of having ASD but had not yet received any treatment were videotaped for a CSBS DP behavior sample (all of the contrast group children were diagnosed with ASD at 36 months of age). The posttreatment group and the contrast group were comparable on communicative means and play, but the contrast group had significantly poorer performance on all other social communication measures.

However, this study design has limitations, one of which is that the differences between groups at post cannot be attributed solely to the treatment, as groups were not randomly assigned and no data was collected for the contrast group before these children were 24 months of age, so it is possible that the groups may not have been comparable at the start. In spite of these limitations, the promising results of the ESI Project have influenced the development of the SCERTS model. More rigorous studies of both the ESI Project and the SCERTS model are needed to truly understand the efficacy of these approaches in treating young children with ASD.

Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)

TEACCH, developed in North Carolina by Schopler and colleagues in the 1970s, is an approach to treating individuals with ASD throughout their life span (Marcus and Schopler 2007). TEACCH is a comprehensive treatment method in that it aims to improve many different areas of an individual's development. Treatment goals and plans are based on each child's strengths, interests, and needs within the context of relationships and the community. This approach does not, however, use typical developmental sequences to guide intervention, as "skills and behaviors are targeted for their functional utility for the individual's future, rather than coming from lists of the typical developmental sequences" (Mesibov et al. 2005, p. 37). TEACCH incorporates traditional behavioral techniques (such as prompting, shaping, and reinforcement), neo-behavioral approaches (such as incidental teaching and functional behavioral analysis), as well as developmentally appropriate practices (Mesibov et al. 2005). The educational strategies in TEACCH are referred to as structured teaching, and capitalize on the strengths and interests of each child and address the difficulties experienced by individuals with autism that affect their learning. In this way, structured teaching strategies often include options for children to process information visually and structured environmental supports to assist children in choosing, engaging in, and making sense of daily activities. TEACCH programs are typically classroom-based programs; however, home-based programs are also available. In both options, parents are trained as co-therapists so that learning can continue in the home setting during daily interactions and routines.

TEACCH meets three of the five criteria of a developmental treatment approach for young children with ASD. The treatment is not based on sequences of typical child development (Mesibov et al. 2005), but the approach is informed by developmental science and the science of learning. It is administered in the context of relationships and is child-centered, as it is individualized based on each child's strengths, interests, and areas of difficulty. However, TEACCH is not play-based, as children are first taught new skills via one-on-one structured instruction. TEACCH is a comprehensive treatment approach, as it focuses on many areas of development. Therapists, trained teachers, and parents administer TEACCH in classrooms and at home. Although TEACCH first teaches children in a highly structured environment, we considered this approach as being offered in both structured and naturalistic settings, as it includes a plan for generalization to naturalistic settings with less structure and includes a home-based component.

There is much efficacy research on the TEACCH approach, including studies all over the world and studies focusing on different components of the model, but many of the studies were conducted on older children and/or adults (see Mesibov and Shea 2010). The two studies reviewed here and described in Table 20.2 were selected because they fit the age range, they span the history of the approach, and they focus on the effects of the comprehensive model and not just on one component of the model. Both of these studies are rated as Type 2 studies (Nathan and Gorman 2002, 2007). Short (1984) compared the amount of parental guidance and stress, as well as appropriate and inappropriate child behavior during a pretreatment wait period to a posttreatment period. All fifteen parent-child dyads (child mean age of 4.7 years) received approximately 5 months of TEACCH intervention, totaling approximately six to eight sessions of 1–1.5 hour of treatment. At the end of treatment, there was a significant increase in the amount of parental guidance and appropriate child behavior during a parent–child interaction. However, the amount of inappropriate child behavior and reported parental stress were not significantly different after the treatment period.

The second Type 2 study by Ozonoff and Cathcart (1998) explored the effectiveness of a TEACCH-based home intervention program for 22 children with autism (2–6 years of age). The first 11 child–parent dyads to enroll in the study received 10 weeks of 1 hour TEACCH-based home program by trained interventionists. In addition, these 11 dyads received a 1-hour clinic visit each week at the beginning of the study, gradually decreasing to one visit every 2–3 weeks. The second 11 dyads received community treatment as usual. In comparison to the community control group, the treatment group improved significantly on the subtests of imitation, fine motor, gross motor, and nonverbal conceptual skills of the Psychoeducational Profile Revised (PEP-R), and in overall PEP-R scores. Although the treatment groups were matched on age, autism severity, initial PEP-R scores, and time interval between pre- and posttesting, groups were not randomly assigned.

Both studies reviewed here demonstrating promising effects of the TEACCH intervention model, however more rigorous study designs including randomized control groups are necessary to yield conclusive results on the efficacy of this intervention. The review of these two studies should be considered in light of the breadth of research that exists on the TEACCH approach.

Conclusion

Developmentally based intervention approaches for young children with ASD are widely known and widely used, in the USA and in many other countries. While the empirical evidence for many of these approaches has lagged behind interventions coming from ABA, this situation is changing due to the enormous increase in emphasis and funding for interventions for the very youngest children with ASD. There are now real choices to be made between empirically based approaches coming from ABA and from developmental science. However, setting these up as dichotomous approaches is more heuristic than real, since developmental approaches that use thoughtful teaching practices are very likely using clear antecedent-behavior-consequences and put parentheses around (ABCs) and careful prompting, shaping, chaining, and fading in their teaching practices, whether they use that language or not. Similarly, early intervention programs developed out of ABA are incorporating concepts (e.g., play and joint attention) from developmental science as they develop curricula for infants and toddlers (Stahmer et al. 2011). It is very likely true that the most effective intervention approaches of the future will bring together the science of learning and the science of child development to individualize interventions and build from the latest empirical findings. While our review attempted to gather information on the field of developmentally based intervention approaches, we were hampered by the lack of a standard definition of a "developmental approach."

Some intervention models that appear to include many components of a developmental approach do not consider themselves to be "developmental," and others that many would not consider particularly developmental label themselves as such. Hopefully interventions that expressly include programmatic aspects derived from developmental science will begin to use the term "developmental," and those that describe themselves as developmental will explicitly state what aspects of their approach come from developmental science. Both professionals and parents would benefit considerably from this kind of "truth in advertising." In this paper, we have offered a definition of a developmental approach; time will tell whether this is of use to the field.

A second aspect of this review that needs comment is the number of "namebrand" intervention approaches that we included. It is interesting that there are so many comprehensive intervention approaches for very young children, and so few for older children, youth, and adults. The availability of comprehensive, branded programs with packaged curricula, assessment tools, and prescribed teaching methods likely reflects the relative homogeneity of very young children with ASD compared to teens or adults with ASD. A developmental curriculum for infants and toddlers with ASD can be modeled from developmental curricula for typically developing infants and toddlers in daycare and nursery school settings. By the time children with ASD are school aged and older, the range of functioning levels, skills, needs, and associated problems is so vast that aspects other than age become the most important "grouping" criteria for developing teaching programs. The fact that very young children with ASD have relatively similar needs for learning speech and language, play skills, social exchanges, nonverbal communication, and early cognitive-perceptual representations allows for comprehensive curricula to be developed. These intervention packages are often quite helpful to parents and early interventionists who are not autism researchers and who need to have help to integrate the vast amount of research that has been conducted on early development and learning in ASD. "It can be quite helpful to the intervention field when a brand-name intervention provides empirically derived efficacy data for its approach and a well-written treatment manual for the public that specifies both the content to be taught (the curriculum) and the teaching procedures to be used" (Rogers and Vismara 2008, p. 31). In addition, the presence of a well-described intervention approach facilitates research efforts. When core issues like curriculum, teaching practices, fidelity of implementation measures, and data collection systems are already defined by the developers, research efforts and replications are much easier to organize. However, by limiting our review to well-studied developmental intervention approaches, by definition we could not review interventions in the beginning of their development, or interventions that grew out of a set of studies in which the developing approach was not yet named. By the time this chapter is in print, there will likely be new additions to the group of empirically based developmental practices. Thus, a review paper like this can never be completely contemporary. There is always a need to search for new papers in order to stay abreast of the field.

In terms of strength of the evidence, we have very few high quality efficacy trials, and no effectiveness trials, of these developmental approaches to early autism. While behaviorally based interventions for early ASD also have few high quality group efficacy studies, there are a plethora of high quality single-subject designs demonstrating experimental control of the dependent variables in the behavioral literature. The lack of a parallel body of work in the developmental interventions likely attests to a previous lack of emphasis on measurement and experimental rigor on the part of developmental interventionists. The current, and welcome, emphasis on empirically based interventions requires intervention studies of all approaches to consider the underlying causal mechanisms, specify expected outcomes a priori, and incorporate high quality measurements into examination of proximal and distal outcomes, as well as fidelity of implementation measures. While developmentalists tend to think of developmental progress as occurring at a different level than day-to-day behaviors, developmental changes are reflected in child behavior changes, and developmental progress can be measured in frequency counts (see Kasari et al. 2006, 2010; Vismara and Rogers 2008; Vismara et al. 2009 for excellent examples). The child development literature is rich with examples of straightforward measures to examine developmental constructs (the Strange Situation comes to mind). Relying on distal standardized test scores as the only critical outcome measures prevents interventionists from examining proximal behavioral probes that can show short-term change and that can allow for greater use of single-subject designs, which are much easier, faster, and cheaper to carry out than controlled group studies. Greater use of high quality single-subject designs would add considerably to the accumulation of evidence for efficacy of developmental approaches. We must find faster ways of moving intervention studies from the lab into the community. Without knowing results from community use of these intervention models, we have no grounded advice to give to families or community practitioners. Studies in community settings need to examine implementation fidelity as well as child and family outcomes in order to help us know how to transfer these approaches from university staff to community groups, and what to expect.

The previously common use of community treatment groups or wait-list groups as comparison subjects is becoming a more and more difficult design for researchers to implement. One reason for the difficulty is the steadily increasing availability of more early intervention services in communities, especially those communities in which a university autism research group might be operating. In some communities, public services are providing the same types of high quality interventions that universities want to test. In a recent study of our own, the community comparison group of 1-year-olds was receiving twice as much intervention as our experimental group! In addition, we have very limited ways of characterizing and comparing community services to experimental services, other than by name brands and number of hours. Such information conveys little about the actual type and frequency of learning opportunities that children receive (Warren et al. 2007), the kind of information that is needed in order to understand what children are actually receiving. Wait-list designs have been considered unethical by some reviewers, since it requires families to wait for interventions rather than beginning them immediately. It is also considered unethical by many to ask families to refrain from beginning additional services during experimental trials.

These kinds of design difficulties indicate a need to move to designs that compare different treatments (as in Yoder and Stone 2006) so that all children quickly receive interventions that are expected to help them. Thus far, we have only discussed designs that examine one type of treatment. However, it is well known that there are good responders and poor responders, in some proportion, in every treatment, and studying one intervention only does not help us understand individual responses to different treatments. Laura Schreibman has been a leader in discussing this issue and carrying out initial studies (Sherer and Schriebman 2005; Schriebman et al. 2009, Schreibman et al. 2011). Studies like hers that examine child predictors of response to one or another treatment, and those that use SMART designs or decision trees within the study (Lei et al. 2012; Sandall et al. 2011) and repeated randomization to various treatment arms, are paving the way for the kinds of studies that the field needs—those that address individual intervention needs of individual children and change the intervention according to progress data in order to maximize treatment response (i.e., Response To Intervention [RTI] approaches).

The need for infant intervention models is now on the horizon, thanks to the work of the infant sibling researchers and early detection researchers. We now have community parents bringing infants to the clinic by 6 months of age with worries about ASD, and some of these children are very worrisome. What are we to do? To “wait and see” is frightening to families who are concerned about ASD and buy into the importance of earlier intervention. To “act now” is very difficult without studies, approaches, curricula, and manuals appropriate for this age. We need to rise to these challenges and develop interventions for risk signs of ASD. Fortunately, there are many high quality studies from the non-autism infant intervention literature from which to draw from initial ideas about how and why (see Wallace and Rogers 2010 for a review). Carefully controlled studies are critical for this group, since we have no idea what these “early signs” mean, and what they foretell, for infants below 12 months of age.

In closing, the gap between treatments derived from ABA and those derived from developmental theory is closing as children with ASD are coming in for services at younger and younger ages, and therapists need to treat children as young as 12–15 months of age. The gap is also being closed as interventionists realize that the models are not necessarily dichotomous. Developmental skills can be taught with the learning tools from ABA, and careful, ongoing skill measurement can occur within developmental approaches. The call for empirically supported interventions brings to the table empirical findings from many fields, and the increasing use of interdisciplinary teams in ASD treatment brings professionals together to work as a unit with a wide range of empirically based practices from which to draw. Early intervention is very fertile ground within which to develop, test, and disseminate transdisciplinary treatment approaches for ASD.

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Recovery and Prevention

21

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Keywords

Recovery · Prevention · Rapid learning

Recovery and prevention are among the two most sought after achievements in the treatment of any disorder. Recovery from autism continues to be a controversial topic, receiving everything from total acceptance in some circles to complete denial in others. Recovery is talked about widely in the community of families affected by autism spectrum disorders (ASD), as well as amongst practitioners of complementary and alternative medical treatments (CAMs), but little has been written on the topic in peer-reviewed scientific publications. The unfortunate result is that families of individuals with ASD are left primarily with unsubstantiated claims that are propagated on the World Wide Web. In the first half of this chapter, we will review definitions of recovery from autism, elaborate our working definition, review existing scientific evidence on the topic, and discuss directions for future research on recovery.

If the concept of recovery from autism is controversial, the concept of prevention of autism is virtually unheard of. In the second half of the chapter, we will discuss a behavioral approach to the concept of preventing autism and describe some initial clinical impressions. Since research on preventing autism has not even begun, our discussion of prevention will necessarily be primarily conceptual. The chapter will then conclude with overall directions for future research.

Recovery from Autism

Our Definition of Recovery

We have described our definition of recovery in two previous publications (Granpeesheh 2008; Granpeesheh et al. 2009), but we will elaborate here. Essentially, our concept of the behavioral manifestation of autism is that a set of skills has not developed or has developed more slowly and inconsistently than those skills in typically developing children of the same age. Recovery is simply the name for the acceleration of the development of those skills, such that clinically significant impairment no longer exists for the child. Some analogies of other skill deficits may be helpful to illustrate the basic point. An adult who never learned to read is called illiterate. Without effective reading intervention, he will likely remain illiterate for the rest of his life. In other words, illiteracy is a “lifelong disorder.” With effective reading intervention, he can learn to read. He is now no longer illiterate, and it would be

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plainly absurd to say that he still "has illiteracy" even though he can read. Traumatic brain injury (TBI) is another useful example. Major skill loss is a common effect of TBI, and the remediation of skill loss is the goal of treatment for it. If a person who incurred a TBI receives rehabilitative treatment and subsequently regains all their lost skills, it is entirely common to say the person "recovered from their brain injury." The same should be true for autism. If a child who was once diagnosed with autism receives treatment that remediates all language and social deficits and eliminates any clinically significant problems with repetitive interests, it is no longer logical to say the child "has autism." He has recovered from autism. Of course, autism is far more complicated than illiteracy and has different etiology from TBI, but there is not a single shred of scientific evidence to suggest that the skill deficits that comprise autism cannot be fully remediated, at least in some children.

Measuring Recovery

The seminal paper by Lovaas (1987) was the first study that attempted to document recovery of children with autism. It is also important to note that it was the first controlled outcome study to document large-scale and relatively long-term treatment effects for individuals with autism. Prior to this study, it was still widely believed that autism was not treatable. In this study, children with autism received 40 h per week of one-to-one behavioral intervention, starting before the age of 3.5 and continuing for more than 2 years. At followup, 47 % of the children who received intensive intervention no longer suffered from clinically significant impairment related to autism. Unfortunately, the only evidence of this outcome that the study contained was IQ scores in the normal range and success in regular education placement without support. McEachin et al. (1993) followed up with the group of children who had recovered and found that eight of nine retained their gains and continued to function successfully with little to no clinically significant impairment.

Stating that a child can recover from autism was quite a large claim to make in 1987. Not surprisingly, many in the autism community had strong negative reactions to the Lovaas paper. It is probably fair to say that most reactions were based as much on bias as on science, but legitimate criticisms were raised as well. For example, Mundy (1993) raised concerns over residual symptoms that may be similar to those displayed by individuals with high-functioning autism. He stated that much more rigorous evaluation of outcome should be conducted before it is prudent to state that children have recovered. Mundy's paper stressed that measuring the phenomenon of recovery from autism demands precise and comprehensive measurement. Unfortunately, most research to this day has fallen short of comprehensively measuring all areas of functioning that are critical, and no consensus yet exists on how to measure recovery from autism.

In 2008, our group proposed the following system for measuring recovery from autism (Granpeesheh 2008). An individual can be considered to have recovered from autism if he once had a confirmed diagnosis of autism, receives a treatment of some sort, and then achieves all of the following:

1. Standard scores of 85 (one standard deviation below the mean), or higher, on valid tests of language, intelligence, and socialization
2. Is included in regular education with no special supports or modifications of any kind
3. Is evaluated by an expert diagnostician and no longer qualifies for any ASD diagnosis, according to DSM-IV criteria, on the basis of his current level of functioning

In the same year, Deborah Fein's research group proposed a similar system of measuring recovery from autism (Helt et al. 2008). They proposed that recovery consists of:

1. History:
    a. Diagnosed with ASD in early childhood
    b. Language delay: No words by 18 months or no word combinations by 24 months
    c. Blind review of charts confirming diagnosis
2. Current functioning
    a. Does not meet DSM-IV criteria for any ASD by best clinical judgment

b. Does not meet ASD cutoff on communication or social subdomains of the ADOS
c. No special education services are being rendered specific to autism symptoms (support for attention, organization, or academic difficulties is acceptable)
d. Individual is functioning without an assistant in a regular education classroom
e. Verbal, performance, and full-scale IQ are all at 78 or above
f. Vineland communication and socialization subscales are at 78 or above

Fein's definition of recovery is similar to ours in most respects, except that it is slightly less stringent in terms of the standard scores that meet the cutoff (one-and-a-half standard deviations below the mean vs. one), slightly more precise in terms of how the history must be measured (i.e., number of words spoken at particular ages), and somewhat more stringent in terms how diagnostics are measured after recovery (i.e., including ADOS in addition to clinical judgment by an expert diagnostician). However, the similarities stand out more than the differences because both models of measuring recovery from autism essentially amount to one basic proposition: If valid measures of all areas of functioning relevant to autism produce results within the average range and the individual is functioning successfully in day-to-day life, it is reasonable to say he or she has recovered from autism.

Research Documenting Recovery from Autism

Sallows and Graupner (2005) evaluated the effectiveness of EIBI, consisting of 38 h per week of behavioral intervention, starting before the age of 3.5 and lasting for 4 years. In addition to the primary purpose of the study, which was to evaluate overall outcome, the study evaluated the characteristics and outcome of a subset of children they labeled "rapid learners." Rapid learners were children who achieved non-impaired functioning on measures of intelligence, language and socialization and were succeeding in regular education. Eight of the eleven rapid learners were receiving no specialized supports in public school, while three had aids because of inattentiveness. Eight of eleven also scored in the non-ASD range on the ADI-R. The Sallows and Graupner study was important because it was among the first to apply a well-accepted diagnostic measure, the ADI-R, to evaluating outcome of children who recovered from autism.

Zachor et al. (2007) evaluated the effects of 1 year of EIBI for children with autism in Israel. They included the ADOS in their battery of assessments. By the end of treatment, 20% of children who had received EIBI no longer met criteria for any ASD according to the ADOS, a gold-standard diagnostic measure. In contrast, none of the children in the control group achieved this outcome.

Most existing research on recovery included relatively small numbers of individuals. In 2009, our group published a retrospective review of the charts of children who we observed to have recovered from autism at our clinic (Granpeesheh et al. 2009). We interviewed our most senior clinicians and asked them to identify all past clients who had recovered prior to discharge from treatment, from 1995 to 2007. This process produced a list of 204 names. The charts of all 204 clients were then reviewed for usable data and 38 charts were identified that had IQ scores taken within 6 months of the beginning of treatment and within 6 months of discharge from treatment. Twenty-four of the charts also had data from the Vineland Adaptive Behavior Scales (VABS). All charts showed IQ in the average to above average range at discharge, and increases were generally seen on the VABS although they were less robust. This was the first study to document recovery in a relatively large group of children with ASD, although the fact that the study consisted of a retrospective chart review severely limited the data that were available for analysis. Further research using thorough measures of recovery, as well as a valid experimental design, was still needed.

In a recent study, Fein's research group published a study that contained comprehensive evaluations of functioning in children with autism who had recovered (Fein et al. 2013). Kelley and colleagues evaluated three groups of children: (1) typically developing children, (2) children who were reported to have recovered from autism, and (3) children who retained their ASD diagnoses but were reportedly high functioning. One of the primary purposes of the study was to determine whether children who recovered from autism had no detectable clinically significant impairment or whether they retained symptoms similar to those observed in high-functioning individuals with ASD. The rationale behind this comparison was to address the notion proposed by some that children do not recover from autism; they merely become higher-functioning individuals with autism. However, overall, the study found no differences between the recovered and typically developing groups, whereas differences were found in several comparisons between recovered children and high-functioning children who retained their ASD diagnoses. The only exceptions were three of the 34 recovered children who showed below average scores on facial recognition. Another common criticism of the concept of recovery from autism is the claim that children who recovered likely never really had autism to begin with. In order to address this concern, the Fein study used blind reviewers to review the original diagnostic charts of both the recovered group and the high-functioning ASD group. The reviewers, blind to group assignment, found that the participants in the recovered group did indeed qualify for ASD diagnoses at the time they were diagnosed. Similar to the Granpeesheh study, the Fein study was retrospective but included significantly more thorough evaluations across a wider range of skills. Taken together, these studies strongly support the notion that some percentage of children recover from autism.

Objections to Recovery

One objection to the concept of recovery is that it denies the individuality of people with autism and seeks to make them "normal." This objection is based on a fundamental misunderstanding of what most, if not all, EIBI practitioners mean by the term recovery. The goal of EIBI is never to make people normal; it is to give them the skills to be whoever they want to be. Social proclivities are a good example. Many individuals with autism prefer to spend time alone rather than making friends with peers. Effective EIBI treatment that aims toward recovery does not attempt to change this. Rather, EIBI treatment aim to teach the individual the skills necessary to make friends if one wants to make friends. If one has never learned the language necessary to make friends with peers, then one can hardly be said "choose" not to make friends. When children recovers from autism following EIBI treatment, they still have their own interests, intricacies, and unique personalities, but they also have the skills they need to live independently and to access the full range of human experiences in life, if they so choose.

The position we are advocating here is that autism is not a personality, a unique perspective, or a different way of looking at the world. All humans, regardless of whether they have autism, already have unique personalities, perspectives, and preferences. Autism is a name for the failure to develop critical skills that allow one to get the most out of life. For example, being particularly aware of visual stimuli does not make one autistic. It may well be true that many individuals with autism display this trait, but so do many typically developing individuals, and it is not something that needs to be addressed by treatment. Similarly, many individuals with autism excel at memorizing facts and enjoy spending free time doing so. Memorization can be a critically important skill for everyone, and effective EIBI treatment does not attempt to remove it; it merely establishes additional leisure and social skills that may be more effective in helping the individual make friends and have fun with peers, if he so chooses.

Another objection to the notion of recovery from autism is exemplified by the statement that one can "still tell the person used to have autism." This is an empirical question that could be settled through blind evaluation. Prospective studies of recovery from autism could include blind evaluation of children who have recovered from autism, as well as typically developing peers of the same age, and the ability to distinguish between these two groups could be directly studied. But more importantly, the very nature of objection to recovery lacks credibility. Being able to tell that someone used to have a disorder does not mean they currently have the disorder. Some describe recovered children as “quirky” or “different,” but quirky and different are not disorders. Certainly, we would not want to live in a world without quirkiness and individuality.

Still another objection to discussing recovery from autism is that it implies that recovery is the only meaningful outcome of treatment and may therefore increase societal stigma attached to individuals who have not recovered. An ASD diagnosis can be quite stigmatizing and a source of significant stress for the individuals and their families, so it is critical that we, as a community, do nothing to contribute to this. Therefore, honest discussion of whether the concept of recovery increases stigma for individuals who have not recovered is probably healthy for the autism community. It is conceivable that an *overemphasis* on recovery as the outcome of treatment could unintentionally imply that it is the only meaningful goal. For example, if the percentage of participants in a treatment study who recovered was the only outcome that was discussed to a significant degree, and no attention was paid to the very real and important gains that the rest of the participants made, the mistaken impression could be given that recovery is the only valued outcome. However, the goal of EIBI has always been clearly stated as maximizing the skill development of each individual person with ASD, such that each can reach his maximum potential, whatever that maximum may be. For some, the maximum potential is recovery. For most, it is not. In the worst case scenario, a child learns basic functional communication (perhaps through pictures or sign language), his challenging behavior decreases, he learns to use the toilet, and he learns to function more independently. These gains, though modest in comparison to recovery, are not modest to the individual who made them and his/her family. Any gains that maximize independence and self-determination and minimize upheaval and frustration in an individual’s life are valuable, and it is important for the EIBI community to be clear on this issue.

Yet another objection to discussing recovery is that most individuals with ASD are too old for recovery to be a realistic possibility. The hopes, dreams, and aspirations of families of adolescents and adults with ASD are critically important and represent the vast majority of families living with ASD today. Some complain that too large an emphasis is made on early intervention and that, when their children reach adolescence, the available supports and opportunities decrease dramatically. Perhaps the very topic of this book (early intervention) reflects this problem. Particularly since the majority of children with ASD will still not recover, even when given the best possible treatment, it is critical that the needs of older individuals with ASD not be ignored. The large emphasis that is currently placed on early intervention is likely due to a number of factors, including the larger amount of funding currently available for research and practice, the relatively larger treatment gains that can be made, and the fact that it is simply easier for practitioners to manage young children, particularly when severe challenging behavior is present. Regardless of the reason for the overwhelming emphasis on early intervention that is present today, a greater degree of attention and resources is needed for older children and adults with ASD.

Finally, some object to the use of the term recovery because they believe it implies that a medical or biological cure has been produced. In other words, since ASD is a biological disorder and no biological or physiological intervention has been done, then there must be some underlying biological disorder and therefore the child cannot have been recovered from the biological disorder. It is our position that autism is not merely a biological disorder. In fact, it is worth noting that, so far, it is still a disorder that is diagnosed *purely* on the basis of behavior, that is, on the basis of how the individual interacts with his or her environment. It is our position that autism is the name used to describe a complex interaction between behavior, environment, and disordered biology. In the case of recovery from autism, the behavior and environment components are removed and what is left is an individual with disordered biology (although this is usually undetectable) who interacts with his or her environment in a non-disordered manner. This is no longer usefully referred to as autism. This is a non-autistic person with an unidentified—and apparently unproblematic—disordered biology.

Sociopolitical Implications of Recovery from Autism

The concept of recovery from autism is very rarely acknowledged in the mainstream scientific community. Today, virtually all mainstream informational websites on autism (e.g., National Institutes of Health, etc.) assert clearly that autism is either a "lifelong condition" or that there "is no cure for autism." Perhaps, by design, such mainstream communities are conservative and not early adopters of information. In science, it is common to reject new ideas until there is overwhelming evidence in support of them, and this tendency is usually a good thing because it staves off premature adoption of erroneous and therefore unfruitful ideas. However, we argue that, in the case of recovery from autism, the clinical evidence is far too large to ignore any longer. Indeed, even in 1987, a small but sufficient number of individuals had recovered from autism, such that the concept should have been wholeheartedly engaged and studied, rather than criticized and marginalized. No particular researchers will be pointed out here (pointing fingers is probably not fruitful), but a large chorus of dissent on the topic of recovery was audible in the scholarly community in response to the Lovaas (1987) paper. It is interesting to note that few or none of the dissenters were experts in autism treatment, and few or none actually engaged the possibility of recovery by familiarizing themselves with the treatment that was said to produce it and contributing to the rigorous scientific study of it. Instead, the vast majority of these researchers merely said "nay" and continued to do research on a myriad of variables that had little or no direct relevance to treatment for individuals with ASD. Recovery was happening more than 25 years ago, and it was clear to anyone who was directly involved in the provision of top-quality EIBI services. Yet, only now the mainstream scientific community is beginning to acknowledge it. Legions of experts in autism research denied the possibility of recovery and discouraged its study and therefore, quite possibly, slowed the progress of scientific research on autism treatment. Conservatism is generally good in science, but we hope that the mainstream scientific community is beginning to recognize that many have been on the wrong side of the recovery debate for more than 2 decades.

On the opposite side of the continuum from the mainstream scientific community, several parent groups and hundreds of practitioners of CAM treatments embrace the concept of recovery far less judiciously than is justified. Virtually every week, a claim is made on the Internet that a new treatment has recovered or cured a child with autism. An exhaustive review of these treatments is far beyond the scope of this chapter, but they run the gamut from ones that have at least minimal legitimate rationale to ones that are wholesale fabrication (e.g., exorcism). CAM practitioners often complain that there is a very real lack of progress in research on medical treatment of autism, and this complaint is indeed justified. Today, there is not a single FDA approved medical treatment for autism. The atypical antipsychotic risperidone is approved for the treatment of challenging behaviors in individuals with autism, but this hardly amounts to a treatment for autism, per se, and hundreds of studies already support the effectiveness of behavioral interventions, which are far less intrusive, for challenging behavior in individuals with autism and other developmental disabilities.

In response to the lack of scientific progress in medical treatment for autism, many CAM practitioners prematurely adopt treatments that may indeed have tertiary data supporting the rationale behind them but have no real treatment data supporting their use or safety. In the overwhelming majority of these cases, the practitioners solicit verbal reports from their patients' parents on the effects of the treatment. It is no surprise that, when parents go to a doctor who thinks a treatment is going to work, and the parents are desperate for something that will work, the parents are likely to believe they see at least some effects.

This is the very reason for placebo-controlled treatment research. However, in the absence of real scientific research, both CAM practitioners and parents alike hold onto any evidence they can, anecdotal reports proliferate on the Internet, and soon tens of thousands of families are implementing treatments for their children that have no research support. It is no surprise, then, that this movement lacks credibility in the mainstream scientific community. An unfortunate side effect is that the world likely notices that the loudest proponents of recovery from autism are also the least judicious in which treatments they advocate. The inevitable result is that recovery is seen as just another outlandish anecdotal story on the Internet.

Practitioners of top-quality EIBI have been producing recovery in some proportion of their clients for decades. It is interesting, then, to note the almost total lack of use of the term recovery by EIBI researchers and practitioners. To our knowledge, less than a handful of EIBI practitioners in the USA publicly acknowledge recovery from autism at the time this chapter was written. It is not clear why this would be the case. However, a likely reason is the harsh criticism that Lovaas received in response to his 1987 paper. Indeed, he even publicly stated that he regretted using the term recovery in print. However, those close to him knew that he fully believed in recovery and continued to see it on a regular basis until he passed away.

EIBI practitioners and researchers generally avoid the topic of recovery, but when it is addressed, euphemisms such as “rapid learning,” “optimal outcome,” “removal of diagnosis,” or “loss of diagnosis” are used. Occasionally, EIBI practitioners will say that a client has “graduated” or has “finished the program.” Often, when pressed for more details, they indicate that the child no longer has clinically significant impairment in any domain and is succeeding in his everyday social, educational, and family life, with no specialized supports. Such practitioners often admit, verbally, that they are afraid to use the term “recovery” because of the negative backlash they anticipate from others. To quote a well-known fable, we believe “the emperor is wearing no clothes” here. The time has come for the EIBI community to stand up and acknowledge the outcome they have been producing for decades. Indeed, it could be argued that, when we produce recovery, we as EIBI practitioners, have an ethical obligation to acknowledge that recovery from autism exists.

Ethics of Recovery from Autism

Some question the ethics of discussing the possibility of recovery from autism, a priori. This view must ultimately reduce to prejudice because no one would question the ethics of discussing the possibility of recovery from cancer, diabetes, depression, alcoholism, or phobias. An anecdotal observation serves as an example. At a conference presentation on the topic of recovery from autism (Granpeesheh et al. 2008), an audience member stated that she believed it was unethical to discuss the possibility of recovery because children with autism in her region were not able to receive funding for intensive services and were therefore highly unlikely to recover. Therefore, she stated, telling their parents that recovery from autism following EIBI is possible for some children would harm the parents by making them distressed. We would suggest quite the opposite. We believe that clinicians have the ethical responsibility to tell their patients the possible outcome of the various treatment options that exist. If economic or logistical variables prohibit patients from receiving the treatment they need and to which they have a right, then the patient should feel distressed, just as any patient should when denied access to a proven treatment for any seriously debilitating disorder. Replace “autism” with “cancer” and the point is clear. Consider vaccine-preventable diseases in third world countries. Would it be more ethical to hide knowledge of disease prevention from citizens merely because they cannot afford access to the vaccine?

Future Research on Recovery

It is the opinion of these authors that recovery from autism exists and that early intensive behavioral intervention produces it in some portion of children who receive it. However, much more scientific work has yet to be done. The future of research on recovery from autism is wide open. Unfortunately, much of the most important research will necessarily be large and costly. The first question that many ask is *Who will recover*? A significant amount of research has been done on predicting response to EIBI treatment, and space does not permit a thorough review of this research. However, several variables have been found to be related to positive response to EIBI, including higher IQ and younger age at intake (Harris and Handleman 2000), as well as less impaired language at intake and higher rates of learning early in treatment (Sallows and Graupner 2005). However, results have often differed across studies, and additional research is needed with larger samples.

Predicting who is likely to recover from autism, in itself, is not likely to improve the lives of individuals with ASD. Indeed, this information, alone, may enable funding sources to deny access to treatment to those who are less likely to recover. What is really needed is research that uses this information as a springboard from which to push the effectiveness of EIBI to new heights. For example, questions such as the following must be directly addressed by research: What is the optimal model of EIBI to produce recovery? How can EIBI be made to produce higher recovery rates? How can EIBI be altered to recover children who otherwise would not recover? It seems likely that a subset of children with ASD learn more slowly in EIBI programs because of particular deficits at intake. For example, children for whom social attention is not already a conditioned reinforcer are likely to be less motivated by the highly social nature of EIBI than children for whom attention is already a large source of motivation at intake. Perhaps focusing more heavily on establishing attention as a conditioned reinforcer at intake would help those children respond better to treatment overall. There are presumably scores of such possibilities, and research into them has scarcely begun.

Future research on recovery should focus on identifying particular ways in which EIBI can be modified or enhanced to contribute to recovery, and then randomized controlled trials should commence, wherein children with ASD are randomly assigned either to a standard EIBI group (in which some percentage of children are going to recover) or to the enhanced EIBI group. The goal of the study would then be to evaluate whether a larger percentage of children in the enhanced EIBI group recovered relative to the standard EIBI group. Research of this sort will need to be very large scale and will therefore be very costly. Even if an important variable is identified, it is not likely to increase recovery rates by more than 5 %, and so a small but important effect of this sort would require a very large sample size in order to achieve sufficient power, particularly given the high degree of intersubject variability that is inherent in ASD research. But logistic and monetary challenges are not a reason to abandon important research endeavors; they are simply barriers that must be systematically addressed and overcome.

Preventing Autism

The concept of preventing autism is all but unprecedented and has not yet been documented in sound scientific research. However, we believe it may be possible to prevent autism via very early behavioral intervention, at least for some children. Furthermore, preventing autism may be less expensive and more efficient than treating it. More importantly, preventing autism should prevent at least some degree of the suffering that the disorder causes for families affected by it. Therefore, we devote the remainder of this chapter to a discussion of the topic. Since little or no research has yet been done on preventing autism, the discussion will necessarily be primarily conceptual.

Defining Prevention

Our concept of preventing autism through very early behavioral intervention is based on our position on recovery from autism. As described above, we believe that it is reasonable to say that,

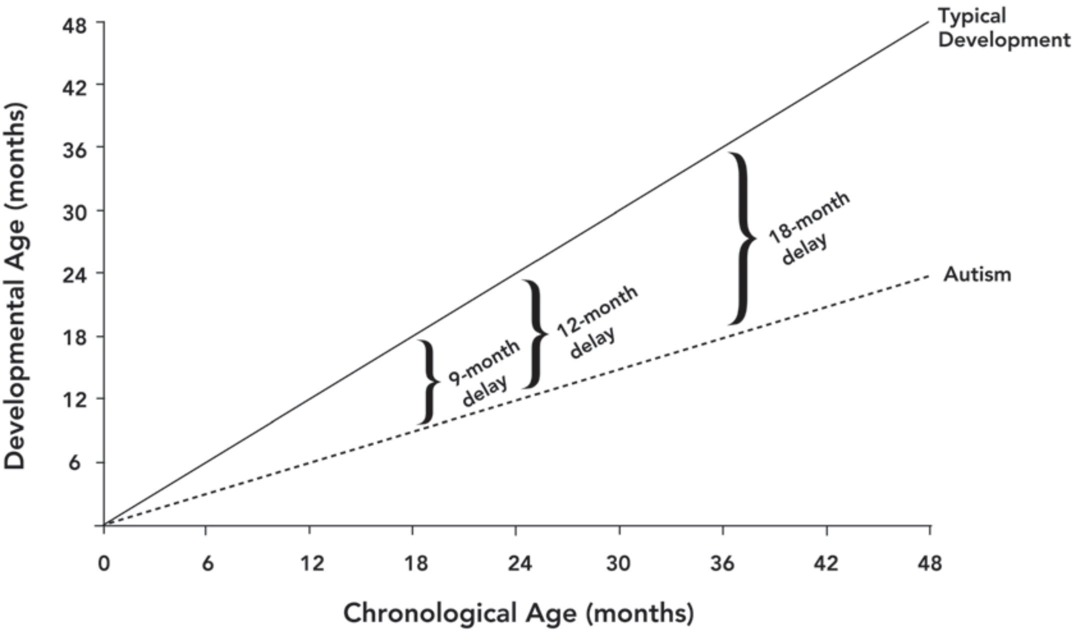

Fig. 21.1 Hypothetical data describing the course of child development in typical children and in children with non-regressive autism. The lower rate of development in autism produces a gradually increasing overall amount of developmental delay as time passes.

if all of a child's clinically significant skill deficits have been remediated via intervention such that he no longer exhibits symptoms characteristic of a diagnosis of autism, he has recovered from autism. We propose that the same basic logic should apply to prevention: If a child exhibits skill deficits that would—without intervention—qualify him for an ASD diagnosis, but EIBI prevents the deficits from reaching a degree of severity to merit an ASD diagnosis, then it is reasonable to say that one has prevented autism.

Figure 21.1 depicts hypothetical child development over time. The horizontal axis depicts chronological age, and the vertical axis depicts developmental age. The solid line at a 45° slope depicts an average rate of development; for example, at chronological age three, the child's developmental age is three. The dashed line depicts hypothetical data for a child with non-regressive autism. The slope of the line is less steep than average—the child with autism is learning at a lower rate—and the vertical distance between the two lines depicts the degree of developmental delay that the child suffers from, at any given chronological age. Since the rate of development is slower for the child with autism, his overall amount of developmental delay gets larger as time passes. For children who present with more severe forms of autism, this gap may be particularly large. Whenever behavioral intervention begins, the goal of intervention is to increase the rate of child development such that the child's developmental age increases to meet his chronological age. If intervention begins when the child is diagnosed at age three, then a delay of 18 months of development must be remediated. As treatment progresses, however, the child's chronological age also increases. Therefore, it is not enough merely to increase the child's learning rate to an average rate because this would merely maintain the total months of delay that were already present. In order to remediate delay entirely, the child's learning rate must *exceed* that of typical development—no small feat for a child with a pervasive developmental disorder.

Since the amount of developmental delay increases over time, it follows that one would want to intervene at the earliest possible time in order to have the least amount of deficit to remediate. For example, if one begins intervention at age two instead of three (on this hypothetical chart), then one has 12 months of delay to remediate, as opposed to 18 months if intervention begins at age three. Our concept of prevention is based on the possibility of beginning intervention before the degree of delay is sufficient to warrant an ASD diagnosis and, therefore when the size of the delay is far smaller than it is when intervention typically begins. Beginning intervention at a chronological age of 18 months is not unreasonable and has become increasingly common in EIBI, as will be discussed below. Beginning at this time would require remediating only 9 months of delay—that is, a hypothetical reduction of 50% in the amount of remediation, compared to beginning intervention at 3 years of age. But if intervention can begin at 18 months of age, there is no reason to think it could not begin at 15 or 12 months of age—perhaps even 8 or 10 months of age.

It is also worth noting that intervening with particularly young children often entails working on more basic skills, which in some cases should be easier to teach. For example, the play skills that a 2-year-old must learn to "catch up" to her typically developing peers are relatively simple (e.g., parallel functional pretend play), versus those that are displayed by a typically developing 5-year-old (e.g., imaginary and sociodramatic play). In short, if one begins intervening when a child is a very young age, one has fewer and more basic skills to teach.

Another possible benefit of very early intervention is the potential for remediating skill deficits before a significant amount of challenging behavior has been learned and reinforced. It is commonly believed that a large portion of challenging behavior that is displayed by children with autism occurs because of a lack of other, more appropriate means of communication (Carr and Durand 1985). If the child is taught successful communication and social interaction skills very early on, then it may be possible to prevent the development of challenging behavior. This, in turn, would likely make treatment more efficient because there would be little or no need to spend the first several months decreasing challenging behavior, as is often done when intervention starts at 3 or 4 years of age.

The hypothetical data in Fig. 21.1 imply that preventing autism should be more efficient than treating it. Research on predictors of successful outcomes for children with autism has indicated that a younger age at intake is strongly correlated with better outcomes (Perry et al. 2011; Harris and Handleman 2000), and it seems reasonable that this same basic logic should stand for prevention, too. In this light, prevention is less of a categorical concept and is probably better conceptualized as a continuum, where the earlier one starts intervention, the less intervention is needed. If one starts it before the diagnosis is made and removes clinically significant impairment before the child is old enough to receive the diagnosis, then one has "prevented" autism. From a purely behavioral perspective, this is no different than behavioral intervention at any other age, except that there is less work to do and it is therefore likely to be more efficient. Additionally, providing early intervention prior to a diagnosis will result in reduction of the "red flag" symptoms commonly used to identify children who may qualify for a diagnosis. These "red flag" symptoms (e.g., poor eye contact, stereotypical patterns of play behavior, etc.) are behaviors that are subject to intervention and can be treated early.

It is important to note that the data depicted in the figure are hypothetical, and it is not known whether the true function describing developmental delay in autism is linear, nor is it known what degree of skill development is possible for any given child. And of course, every child with ASD is different, with some presumably being more severe than the hypothetical data depicted in the chart and some less severe. In addition, beginning EIBI at such a young age has not yet been evaluated in rigorous scientific research, so a large number of variables warrant discussion, several of which we address in detail below.

Research on Autism Prevention

No published studies of which we are aware have specifically set out to prevent autism via very early behavioral intervention. However, one case study described results of very early behavioral intervention for a toddler at high risk for autism. Green et al. (2002) reported the case of a little girl, Catherine, who received an "at risk" diagnosis of autism based on multiple screenings indicating communication and language delays, as well as stereotypic patterns of behavior. The parents of this child sought professional evaluations at the first signs of these delays because of their prior experience with their first child, who had received a diagnosis of autism and was receiving behavioral intervention. At the early age of 14 months, Catherine began an intensive in-home behavioral program consisting of 1:1 direct instruction for 25–36 h per week. At the age of 4 years and 5 months, Catherine completed her 1:1 in-home instruction but continued to have monthly follow-up observations in her preschool classroom. At the age of five, Catherine entered a general education kindergarten classroom without a diagnosis of autism, an individualized education plan (IEP), or a classroom aide, and she did not meet diagnostic criteria for an autism spectrum diagnosis. This case study represents a critical first step in research on using very early behavioral intervention for the prevention of autism, but much more research using valid experimental designs is still needed.

A highly controversial 2004 paper proposing a purely behavioral etiology of autism also contains a discussion of the prevention of autism (Drash and Tudor 2004). Space does not permit a discussion of the main thrust of the Drash and Tudor paper—that autism is caused solely by parent-child interactions—nor is one needed. It will suffice to say that such an idea is bordering on irresponsible in that it is essentially a return to the notion that autism is caused by bad parenting. We find this notion plainly absurd and not even worth discussing. The authors do specifically state that "Our analysis in no way attempts to blame parents" (p. 60), but it seems plainly obvious that denying the contribution of any factor other than parent behavior will carry that extremely negative implication for many parents.

Aside from the controversial aspects of the argument, the Drash and Tudor paper is one of the very few existing papers that discusses the possibility of preventing autism through very early behavioral intervention, and it makes an important practical point: Regardless of the genetic contributions to the etiology of autism, the only level at which we can intervene now or any time soon is the level of behavior—environment relations. The authors give specific recommendations for how this might be done. They propose that within the first 18 months of life or less, at-risk children should be identified, and parent–child interactions should be modified in order to encourage the development of adaptive forms of child communication and decrease avoidant behavior on the part of the child. Furthermore, they describe several case studies in which this was done and report that development for all the children was corrected in a much shorter period of time than is typically required of EIBI for children already diagnosed with autism. Like the Green case study, these were uncontrolled case reports, and further replication with sound experimental designs is still needed.

Identifying Who Should Receive Preventive Intervention

The first obvious roadblock to preventing autism via EIBI is simply detecting at a very young age which children will later be diagnosed with an ASD. Although warning signs can be observed at very young ages, the vast majority of diagnosticians are highly hesitant to provide an ASD diagnosis before 2–3 years because diagnostic evaluations were not validated with younger children (Crane and Winsler 2008). Research in this area has advanced significantly, but results still vary dramatically across studies. Retrospective studies have been published that reviewed home videos of typically developing children and children who later received a diagnosis of autism, indicating that some deficits can be observed as early as 4–6 months for motor anticipation (Brisson et al. 2012), and on average around 7 months for social attention, affective responsiveness, and prelinguistic vocalizations (Crane and Winsler 2008). Another retrospective video analysis has reported that some sensory-motor and social symptoms may categorize children later diagnosed with autism from those later diagnosed with developmental delays and children of typical development at 9–12 months (Baranek 1999). These symptoms include poor visual orientation/attention to nonsocial stimuli, prompted or delayed response to name, excessive mouthing of objects, and aversion to social touch. Similar results were found by Osterling et al. (2002) in a retrospective video analysis of 1-year-old infants later diagnosed with autism versus intellectual disabilities showing that the children who were later diagnosed with autism rarely looked at others or showed an orienting response when their names were called as compared to children later diagnosed with intellectual disabilities.

Although several autism screening tools exist, very few were developed and have been validated for children younger than 2 or 3 years old. One promising screening tool is the Checklist for Autism in Toddlers (CHAT; Baron-Cohen et al. 1992) which includes screening items for children as young as 18 months. The CHAT includes nine items asked to the caregivers and an additional five items that require direct observation in the home. To validate the accuracy of the CHAT, Baron-Cohen et al. (1992) administered the checklist to 41 children considered at high risk for autism based on genetic predisposition and determined that four children consistently failed items assessing gaze monitoring (e.g., looking in the direction of a caregiver's gaze), protodeclarative pointing (e.g., pointing at objects to direct another's gaze toward the object), and pretend play. These behaviors develop in typically developing children around 14 months of age and appear to be distinctively deficit among children with autism. All four children in the sample received a later diagnosis of autism, whereas the remaining 37 children did not fail more than one of these three items and none received a diagnosis of autism. Extending on this initial analysis, Baron-Cohen et al. (1996) administered the CHAT to 16,000 children in Great Britain, and 12 were identified as being at high risk for autism based on failing the three critical items from the initial analysis. Of the 12 children identified as at risk, 10 later received a diagnosis of autism and the remaining two were diagnosed with developmental delays, demonstrating that the CHAT was a fairly accurate indicator of autism at 18 months. A follow-up study investigating the total number of diagnoses on the autism spectrum from all 16,000 participants identified that 94 children had a diagnosis of either autism or PDD at 7 years. Using less stringent criteria to assess which items on the CHAT were most likely to indicate which children may have been identified at 18 months, only 38 % of the 50 cases would have been flagged at 18 months. Although the sensitivity is quite low, the specificity, or likelihood that the instrument will not falsely predict that a child has autism, is quite high (97.5 %) because, out of the identified cases, very few did not actually receive a diagnosis. The concern with using this instrument is that a child may not be flagged on the screening at 18 months, thus missing the opportunity to receive intervention until later, when greater deficits are apparent.

The requirement for direct observation necessary to administer the CHAT makes this screening tool less likely to be used despite its potential benefits of detecting early signs of autism for some children exhibiting symptoms at 18 months. Additionally, some behavioral deficits may not present during a single observation. Because of these potential limitations, a modified version of the CHAT was developed that can be conducted during normal visits to a family pediatrician by relying on parent report of current behaviors. The Modified Checklist for Autism in Toddlers (M-CHAT: Robins et al. 2001) includes 23 items that require a caregiver to provide a yes or no response. The authors validated the M-CHAT by administering it to 1,293 children between 18 and 30 months of age resulting in 58 cases identified as at risk for autism. A full evaluation was then conducted with the children identified as at risk and resulted in diagnoses of autism or pervasive developmental disorder (PDD) for 39 of these children. The remaining 19 children were found to have other language or global delays but did not meet full diagnostic criteria for autism or PDD NOS. Based on these findings, the M-CHAT may be a valuable screening tool that can be easily administered during a child's 18-month pediatric visit, but follow-up research is necessary to determine the number of children who were not identified by the M-CHAT and later received a diagnosis. Although both the CHAT and M-CHAT are promising early screening tools, they are both designed for children at least 18 months of age. With research suggesting that red flag symptoms may be observed within the first year of life, there is a need for much earlier screening tools to identify children who may benefit from even earlier intervention and the possibility of preventive intervention.

There are a few other early screening measures with initial studies demonstrating promising results, but further evaluation of these tools is necessary. These include: the First Year Inventory (FYI: Reznick et al. 2007), a parent report measure administered during 12-month pediatric checkups; the Autism Observation Scale for Infants (AOSI: Bryson et al. 2008), a direct observation assessment that can be administered to children as young as 6 months; and the Infant-Toddler Checklist (ITC: Wetherby et al. 2008), a parent questionnaire that can be administered repeatedly with children 6–24 months old. Efforts are underway to improve the predictive power of these and other assessments for children at risk for developing a later diagnosis of autism, with the goal to identify children that will benefit from early treatment and potentially prevent a diagnosis altogether.

Appropriateness of EIBI Procedures for Infants and Toddlers

One potential concern with very early behavioral intervention, for preventing autism is that the treatment procedures used in EIBI may not be appropriate for infants and toddlers (Dawson et al. 2010). Adapting procedures from one population to another always presents unique challenges, but the concern over using behavioral procedures for very young children is primarily due to a confusion of principles with procedures. The basic principles that are the foundation of EIBI (e.g., reinforcement, extinction, stimulus control, generalization, etc.) were originally derived from research with animals, and their generality has been replicated across scores of species and populations, including human infants (Pelaez et al. 2012). EIBI *procedures*, however, are specific operations derived from the basic principles, such as discrete trial training, natural environment training, chaining, and so on, and these clearly need to be customized to each different population to which they are applied, indeed, to each individual client within each individual population. Just as a smaller scalpel may be needed for pediatric surgery than for surgery on adults, the specific operations by which positive reinforcement are delivered, prompting is delivered, and so on, will need to be adjusted to be appropriate for infants and toddlers. But such adjustment is a natural part of EIBI treatment already and represents minor changes in how a procedure is done, not a question of *whether* it is done. For example, prompting consists of providing extra assistance to ensure a correct response—the particular form of extra assistance does not matter as long as it is nonintrusive, is successful in aiding a correct response, and can be faded out when no longer needed. Any time a child is attempting to learn something new, prompting will be helpful and will therefore still be included in whatever form is developmentally appropriate for the learner.

Similarly, discrete trial training (DTT) is probably the most empirically supported teaching procedure for children with ASD (see chapter on DTT in this volume). It seems unlikely that DTT at the level of intensity and duration that is often done with 3-year-olds would be appropriate for a 1-year-old. But the basic principles behind DTT—many learning opportunities, clear expectations, clear consequences, and providing assistance when needed—would still be needed if maximum learning rate is desired. Therefore, it seems likely that a somewhat “softened” version of DTT would be implemented, perhaps more in the context of play, or that very short blocks of DTT would be implemented—perhaps only two or three trials at a time.

Long-term Outcome

Children who receive preventive behavioral intervention and subsequently do not receive an ASD diagnosis would still need to be followed up in order to ensure that clinically significant ASD symptoms do not emerge at a later time.

Ideally, a lack of ASD diagnosis for life would constitute the purest definition of prevention. In reality, initial research that shows the absence of symptoms qualifying for a diagnosis at age 3–5 would be enormously valuable. After this effect is documented, more longitudinal research documenting continued success in middle childhood and adolescence would be needed. Since it is still not known what causes autism, it seems possible that the genetic and environmental contributing factors may still be present when preventive intervention is discontinued and that they may exert further influence at future times of stress in the child's life, such as when he/she enters school full-time, transitions to middle school, or enters puberty.

Objections

One potential objection to our position on prevention is that, even if it works, one would not be preventing autism; one would merely be preventing the child from receiving the diagnosis of autism. This is not a very meaningful objection because autism, as a disorder, is identified solely on the basis of a behavioral diagnosis, so prevention of that diagnosis amounts to prevention of the disorder. Clearly, this assumes that the child is evaluated by an expert diagnostician and no information is withheld, and they still do not qualify for the diagnosis. Very early behavioral intervention would, of course, no prevent the child from inheriting the genetic susceptibility of developing autism, but the genetic susceptibility is just that—*susceptibility*; it is not a disorder unless it manifests in clinically significant impairment in functioning. A similar objection is sometimes made against the concept of recovery by saying that treatment may change behavior, but it does not change "who the person really is" or that the "person is still autistic, even if they are able to fully function in life without impairment." This objection to recovery is particularly absurd and seems to be based on the assumption that autism is "who the person is," rather than a name for clinically significant impairment across three areas of functioning. We believe that a person is himself, not a disorder. A unique and interesting personality paired with a genetic susceptibility to autism is not autism. It is a unique and interesting person.

Discussing the prevention of autism long before scientific evidence has documented it may be a further source of ethical concern for some. It is important to point out that our definition of preventing autism cannot be applied in a practical way to any particular child and should not be used in such a way by clinicians or researchers. By definition, if our definition of prevention is achieved, one would never know with any degree of certainty whether the child would have been diagnosed with autism if he had not received very early behavioral intervention. Therefore, we do not feel it is ethical at this point to tell parents that one *is going to prevent* their child from developing autism or, after implementing very early behavioral intervention, that one *has prevented* the child from developing autism. All that can be honestly said is that skill deficits should be addressed and that this should be a particular priority for a child who is showing warning signs of autism and has an older sibling with the disorder. It is therefore somewhat alarming that, at the time this volume is being printed, multiple websites exist that provide non-research-based medical information on how one can prevent autism. Thus, it appears as though the concept of prevention is already beginning to receive the same treatment that the concept of recovery has received for the last 25 years: Virtually no research by the mainstream scientific community and irresponsibly premature adoption by the CAM community.

Discussing the concept of preventing autism must be done with care, but a strong argument can be made that *avoiding* the discussion is ethically questionable. A lively interdisciplinary engagement of the topic is going to be needed if sufficient research is going to be allocated to it. Furthermore, we believe it is important to use the word *prevention*, not some other euphemism that is less controversial. Just as in the case of the term recovery, we believe avoiding the use of the word prevention merely serves to marginalize the concept and therefore make it less likely that it will be addressed by serious scientists. To avoid giving the term the full respect of calling it what it is does a disservice to the population of children who may develop autism in the future if effective preventive treatments are not researched.

Funding Preventive Treatment

At the time this volume is going to print, very little funding is available for preventive treatment. This is no surprise, given the lack of research supporting it. However, as discussed already, it makes sense to begin treatment as soon as deficits are observed, therefore preventing the child from falling further behind. Unfortunately, intensive behavioral intervention can exceed US$ 40,000–US$ 60,000 on average per year, and funding is often contingent on a diagnosis (Chasson et al. 2007); therefore, funding for services is usually not available until global deficits are demonstrated and a diagnosis is provided. Nevertheless, funding for early intervention is occasionally available, particularly when a child has an older sibling with a confirmed ASD diagnosis, and so it has become increasingly common for EIBI treatment providers to begin treatment of younger siblings at earlier and earlier ages.

Future Research on Preventing Autism

Our hypothesis, that preventing autism is possible via very early behavioral intervention, must be tested with sound, controlled research. However, such research is going to be enormously challenging. An ideal outcome study on prevention might include the following steps: (1) identify a treatment that is likely to prevent ASD, (2) identify very young children who are highly likely to be diagnosed later with an ASD, (3) randomly assign the participants either to receive the treatment or control, and (4) follow-up at age three or four and evaluate whether more children in the control group have a current diagnosis of ASD than in the treatment group.

One major potential methodological problem is that a very small number of children are likely to later receive any ASD diagnosis, regardless of treatment. Even in the highest risk groups, many children will not develop autism even without intervention. Therefore, many individuals in the control group would not develop autism as well. Detecting an effect this small, especially relative to the overall makeup of the group, would be statistically very challenging. It could require group sizes in the hundreds of participants, making such research very costly and logistically challenging. It is likely that large-scale grant funding and multi-site collaborations would be required for a study of this scale.

A major potential ethical concern with such a study is the need for a control group that does not receive very early behavioral intervention. In other words, in order to produce a controlled demonstration of prevention, one needs a group of children whose autism was *not* prevented. At first blush, this would appear clearly ethically unacceptable. However, the study might be ethically acceptable because treatment would not be *withheld* from children in the control group; they would merely receive what everyone else in their community receives if they had not participated in the study. This ethical concern could be further mitigated by strongly recommending to families in the control group that they seek behavioral intervention elsewhere. If they succeed in doing so, they would need to be dropped from the study, but at least they would be receiving treatment. In addition, some families still choose not to receive behavior analytic treatment, even when they are fully informed of its research base and even when the treatment is fully funded by a third party.

Conclusion

In conclusion, it is our position that recovery from autism exists, and preventing autism may be possible. Both concepts are based on the same basic rationale: If clinically significant impairment is not present, the diagnosis of autism is not appropriate. If an individual once had an ASD, received treatment, and no longer suffers from clinically significant impairment, it is reasonable to say this individual has recovered from autism. Much more controlled research is still needed on recovery. Research is needed to identify which children are likely to recovery, but much more important, research is needed to identify which children will not recover and how EIBI can be enhanced to help these individuals achieve more than was ever possible before.

If children who were going to develop an ASD receive behavioral intervention early enough and they no longer suffer from clinically significant impairment that justifies an ASD diagnosis, then it is reasonable to say that autism has been prevented. Of course, it is not, and perhaps will never be, possible to confirm this at the level of the individual child, but through comparisons across groups, it is entirely possible to test this hypothesis. Not only is it ethical to discuss the possibility of preventing autism, we propose that it is our ethical *responsibility* to do the research that is necessary to determine whether the prevention of autism is possible.

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Mainstream Education for Children with Autism Spectrum Disorders

22

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Keywords
Mainstream · Segregation · Inclusion

> Education, then, beyond all other devices of human origin, is the great equalizer of the condition of men—the balance-wheel of our social machinery. I do not mean that it so elevates the moral nature as to make men disdain or abhor the oppression of their fellow men…But I mean that it gives each man the independence and the means by which he can resist the selfishness of other men. (Mann 1848)

It is a truth that should be universally acknowledged that apartheid is an evil. It is a moral imperative to remove any form of discrimination based on inappropriate and irrelevant personal characteristics from society; indeed, it may be claimed that the development of a civilized society has paralleled the fight to destroy such odorous practices. The engagement of an individual with society can only be premised by mutual protection, and the functioning of individual can only be guaranteed by the protection of that individual from unfair impositions.

Education has long been regarded as being at the forefront of this critical process: not only as a weapon in this struggle, a thought that can be traced to antiquity (Plato's *Republic*), and, importantly, to the beginnings of contemporary focus on state-provided education (e.g., Mann's "The case for public schools"; see Good 2008), but also in terms of the appropriateness of education's own procedures, from the development of curricula by the great Alcuin of York in the eighth and ninth centuries, to the contemporary discussions that underlie the arguments outlined in the current chapter about which (and how) people should access these curricula (Kauffman 1989; Nirje 1969; Warnock 2005).

It is in the light of these considerations that the issue of educating children with autism spectrum disorders (ASD) in mainstream schools has to be debated (see Mesibov 1990). In order to develop appropriate strategies to help these children when they are placed in mainstream schools, it is necessary to understand the philosophical, political, and educational driving forces that place them in mainstream settings in the first instance, and the difficulties that some of these children may have in those settings.

To be clear from the start, the issue of mainstream education for children with ASD is completely shot through with political agenda (see Bricker 1995; Kauffman 1989), ill-defined purpose (Warnock 2005), and incomplete data on which to base decisions. The practice of educating children with special needs, including those with ASD, within mainstream schools has clearly

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been driven by a philosophical human rights agenda: “inclusion and participation are essential to human dignity and to the enjoyment of human rights” (UNESCO 1994; see also Lindsay 2003; Norwich 2005). However, the simple ascertain that the inclusion of children with special educational needs (SEN) into a mainstream school, and the removal of exclusive educational practices, is both a moral and social imperative (e.g., Novick and Glanz 2011), risks falling foul of the concept that is held central to most civilized societies; that is, the right of the individual to the most appropriate treatment (see Barrett et al., 1991). Indeed, it must not be forgotten that a prime motivator in educational change is not abstract philosophical arguments about rights, but it has always been the evidence of the impact of practice on the individual and society; when special schools were initially set up over 200 years ago, they were so established to help educate previously uneducated individuals (Simmons 1978), and when they have been criticized, especially in the context of ASD, it was on the grounds that they were not educating these children to their potential (see Rutter et al. 1967).

Quite simply, at the moment, it is impossible to say that education in a mainstream environment is either good or bad for individuals with ASD; firstly, as the evidence is not present in any great quantity or great quality (see Davis et al. 2004a; Humphrey and Parkinson 2006); and secondly, and more importantly, because the concept of imposing a wholesale policy on a whole group of individuals, merely because of a shared, and highly variable, diagnostic label (see Lord and McGee 2001), may be just another form of inappropriate discrimination. Thus, the research imperative is to identify the evidence of the impacts of mainstream education of children with ASD, and, to establish when and how this approach to education is most likely to benefit those individuals to whom it is applied. We cannot simply believe in mainstream schools or believe in special schools, like we might believe in God, we must believe in the form of education of the individual that produces the best results, wherever that individual is placed.

Pupils with ASD in Mainstream Schools

Current estimates of the population prevalence suggest that between 0.9 and 1.5 % of individuals have ASD (Baird et al. 2006; Baron-Cohen et al. 2009; McManus et al. 2009). Estimates of the numbers of children with ASD who attend mainstream schools in the UK suggest that their inclusion in these settings displays an increasing trend. For example, in an initial survey, Barnard et al. (2000) found that around 50 % of children with ASD that they surveyed received their education in mainstream schools. Keen and Ward (2004) and Frederickson et al. (2010) have since suggested that most newly diagnosed children with ASD are now being placed, at least initially, in mainstream school settings. This latter observation resonates with even more recent estimates of the numbers of children with ASD being placed in mainstream schools that suggest around 60 % of these children are included in mainstream educational settings (Waddington and Reed in press; see Table 22.1), a figure that is broadly consistent with that for all children with SEN (Department for Education and Skills 2006).

At this point, it should be noted that the situation in the UK may be somewhat in advance of that in the USA, where figures imply that just over a quarter of children with ASD are in mainstream education (Individuals with Disabilities Education Act 2004). As will be noted below, there are historical reasons for this difference, which, in themselves, have implications for approaches taken to educating children with ASD in the mainstream, and which may need to be considered when assessing the evidence laid out in this chapter.

In the above-mentioned study by Waddington and Reed (in press), a number of education authorities in the UK were surveyed (combined population = 919,000), and the school placements of the children with ASD in these areas were extracted from the authorities’ records. Although it must be acknowledged that the practice across the four individual authorities varied, further inspection of these data (see Table 22.1) shows that the majority of pupils with ASD in these authorities

Table 22.1 Autistic severity and school placement reported by Waddington and Reed (in press)

		School placement		
		Mainstream	Special	Unit
Diagnosis	Autism	59 % (46)	35 % (27)	6 % (5)
	Asperger's	61 % (11)	28 % (5)	11 % (2)
Mean autism severity (standard deviations)	Total ABC (31–155)	50.9 (2.5)	64.0 (4.6)	54.0 (1.8)
	Sensory subscale (0–27)	7.9 (0.5)	9.4 (0.9)	8.1 (0.3)
	Relating subscale (4–38)	15.1 (0.7)	19.3 (1.2)	16.6 (0.1)
	Body and object use subscale (0–38)	8.9 (0.6)	11.2 (1.2)	9.6 (0.2)
	Language subscale (0–31)	8.5 (0.6)	10.3 (1.1)	8.0 (1.1)
	Social and self help skills subscale (6–25)	10.4 (0.5)	14.0 (0.8)	11.6 (0.1)

combined were placed in a mainstream school, or in a unit attached to a mainstream school. This study also assessed the severity of ASD symptoms (using the Autism Behavior Checklist (ABC)), and it was noted that the children with ASD who were placed in special schools tended to have more severe autistic symptoms and traits than their peers with ASD in mainstream schools (especially on the "relating" and "social and self-help skills" subscales of the ABC). A similar finding of differential placement based on the child's functioning was noted by Eaves and Ho (1997; see also Buysse et al. 1994), who assessed the likelihood of a child with ASD being placed in a mainstream school, a unit attached to a mainstream school, or a special school, and found that this varied with their level of intellectual functioning as measured by the Wechsler Intelligence Scale for Children—Revised (Fig. 22.1).

The comparison between the numbers of children with ASD placed in mainstream schools reported initially by Barnard et al. (2000), and subsequently by Waddington and Reed (in press), chimes with the suggestion that there was around a 15 % increase in the placement of such children in mainstream schools between 2004 and 2009 (Frederickson et al. 2010). In fact, it is important to note in the context of discussing "inclusive" educational practice, individuals with ASD are the only SEN group that is increasingly represented in mainstream schools; the presence of all other SEN-related diagnoses are decreasing in mainstream schools, at least in the UK (Office of National Statistics 2004, 2009). These changes are possibly a product of diagnostic substitution (Matson and Shoemaker 2009; Shattuck 2006), the closure of special schools (Department for Education and Skills 2006), or of the selection policies of schools that tend to make it harder for children with SEN to be accepted in those schools (see West and Hind 2006).

Thus, it can be assumed that at least 60 % of children with ASD are being educated in mainstream schools. Given that this could translate into between 0.5 and 1 % of the child population, this is a sizable issue. The consequences of educating pupils with ASD in mainstream education, the problems of this approach, and how can these problems be overcome is undoubtedly a topic of importance beyond the context of ASD. In fact, the mainstream education of pupils with ASD is an issue that has already merited special consideration, even within the overarching context of SEN mainstreaming (see Norwich and Lewis 2005; Warnock 2005). The stark statistic is that pupils with ASD who are educated in a mainstream school are 20 times more likely to be excluded from that school than their typically developing peers (Department of Education and Skills 2006). Moreover, 20 % of pupils with ASD will be excluded or suspended from their school at least once (Barnard et al. 2000), compared to

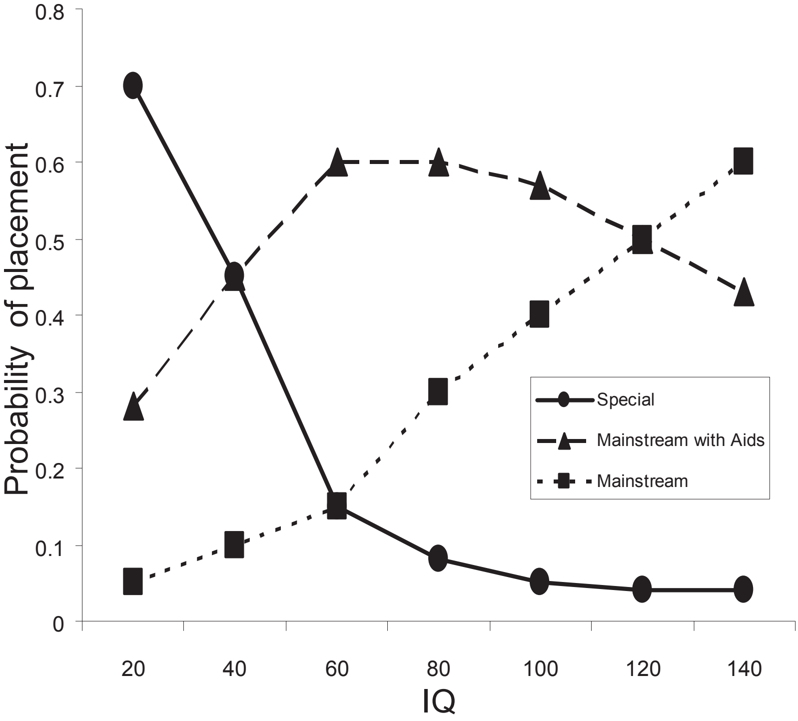


Fig. 22.1 Class type probability as a function of IQ. (Eaves and Ho 1997)

only 8 % of children with another SEN diagnosis (Department for Education 2011). There are also higher levels of behavioral problems in children with ASD in a mainstream setting compared to their typically developing peers (Ashburner et al. 2010), and these pupils exhibit higher levels of emotional problems (Macintosh and Dissanayake 2006).

It might be important also to note that there are numerous reasons why pupils with ASD are being educated in mainstream schools. Most children with ASD in mainstream settings will be recognized as such, and will have been deliberately placed in a mainstream setting, either to promote an inclusive education agenda, or because there are no special schools available. However, it may well be that there is a subset of individuals with ASD in mainstream schools who have not been diagnosed (Humphrey 2008), and who have developed strategies to cope with the problems that this form of education presents for them (Batten et al. 2006). This group presents, what Connor (2000) has termed, an “invisible problem,” and this group may receive no help, even though it may be necessary (see Lord 2011). Moreover, an undisclosed diagnosis can lead to increased negative reactions on the part of the included child’s peers (Ochs et al. 2001). The size of this issue can actually be estimated. Baron-Cohen et al. (2009), comparing the SEN register to a screening procedure conducted across a sample of the schools (both mainstream and special) included on that register, suggested that there may be as many as 40 % undiagnosed cases of ASD in children in schools, although it is not clear whether this proportion was similar in mainstream and special school. Similarly, Kim et al. (2011) suggested that a remarkably high number of children in mainstream school may display signs of ASD in diagnostic tests, but those children either do not require or do not receive any help. In this South Korean study, there were prevalence rates of over 3.5 % in male pupils and 1.5 % in female students. This latter statistic corroborates an increasingly accepted view that ASD is underestimated in females (see also Attwood 2007; Gould and Ashton-Smith 2011). As this “invisible” group receives no support, they may be particularly vulnerable to the range of issues that can beset pupils with ASD in mainstream (and indeed any) schools. These problematic issues include social isolation (Bauminger and Kasari 2000; Humphrey and Symes 2010), and even the onset of comorbid psychiatric problems like depression (Barnhill and Myles 2001; Ghaziuddin et al. 2002). In the development of mainstream education for pupils with ASD, it is of paramount importance to suggest ways these problems can be overcome in both the visible and invisible ASD populations. It is these well-recognized problems that form the basis for interventions and programs aimed at enhancing the mainstream education of children with ASD.

The Pendulum of Segregated Education and Its Relation to ASD

The inclusion of children with SEN in mainstream educational settings has been a controversial concept in education for nearly two centuries. It remains so today because it relates not only to educational values, but also to social values and to a person's sense of individual worth. Any discussion about the education of children with ASD in mainstream should, therefore, be placed in the wider context of the discussions regarding appropriate education for children with SEN. This will serve to highlight the key concerns regarding mainstream education for children with SEN and offer an important perspective to the current discussion as, for most of this period, children with ASD were covered by the broader terms applied to children with SEN (see Frith 1989). Moreover, even a brief overview of the development of the study of ASD reveals that determining the appropriate education of children with ASD has been intimately connected to the conception of ASD (see Kanner and Eisenberg 1955; Lovaas 1987; Yarmolenko 1926).

The history of education for children with SEN across different countries and the development of the concept of ASD are outlined in Table 22.2. Inspection of this timeline reveals that in many countries (other than the UK), for much of the period covered, the debate about SEN policy was not primarily about education, but rather it was about sterilization. For example, in the 1930s, between 60,000 and 70,000 children with SEN were sterilized in the USA (Fennell 1996), where the concept of educating children with SEN only became enshrined in law in 1975. Similarly, in 1933, Germany introduced laws about compulsory sterilization for people with learning disabilities, as were also in existence in Norway, Denmark, Sweden, and Switzerland (see Roy et al. 2006 for discussion). This approach to individuals with SEN was rejected in the UK in 1934 after a brief consideration by the Brock Committee.

Schools based on special needs (for visually impaired and physically disabled pupils) began to appear in the UK from about 1865 (Gillard 2011). After the extension of educational provision to the working classes in the late nineteenth century (Education Act 1870), increasing numbers of "working class" children were excluded from school due to their learning and behavior problems; a "class" imbalance problem that still persists today with nearly 90% of all children subject to school exclusions coming from manual/semiskilled or unemployed parental backgrounds (Daniels et al. 2003).

The exclusion of slow learning and emotionally disturbed children from general educational settings created a difficulty, as many of these children were actually legally entitled to an education by the 1870 Education Act. The solution was an expansion of the special school sector from a prime focus on physically disabled and sensory-impaired children to those with what now would be termed a learning disability. The acceptance that some children excluded from mainstream schools should receive education also led to a dichotomy in the way in which individuals with special needs were treated. Children with severe learning difficulties—then called "educationally subnormal"—were not considered capable of benefiting from education and did not attend schools, but rather were provided with training centers. In contrast, individuals with SEN who were thought to benefit from education—then often termed "feeble-minded"—were provided with places in schools that catered for their special needs. Simmons (1978) documents how the UK Mental Deficiency Act of 1913 cemented the increasing use of the term "feeble-minded,"

Table 22.2 Schematic of timeline of major events in the inclusive education debate in the UK and elsewhere

Date	UK	USA and Elsewhere
1860s	First special schools for physical problems	
1870	*Education Act (1970)* Expands right to education to working classes	
1900–1950	*Mental Deficiency Act (1913)* Introduces concept of "feeble-minded" but educable	60,000–70,000 individuals with learning disabilities sterilized
	Brock Committee (1930) Rejects sterilization for those with learning difficulties	Law for the Prevention of Progeny with Hereditary Diseases (Germany, 1933)
1950–1979	Warnock Report (1978) Calls for inclusive education for all	20 % of individuals with SEN receive an education
		Rehabilitation Act (1973) Introduces notion of right to education for persons with disabilities
		Rolf v. Weinberger (1974) Reveals around 100–15,000 people with SEN sterilized
		Education of all Handicapped Children Act (1975)
1980	*Education Act (1981)* Introduces SEN statements and right to help with mainstream education	
1990s		Individuals with Disabilities Education ACT (1990)
		U.N. Salamanca Statement (1994)
2000s	Education Act (2001) Mainstream placements should be the norm	No Child Left Behind Act (2001)
	Warnock Report (2005) Concludes inclusive education is not working	

and led to further increases in the use of special schools in the UK.

Although the passage of such education acts in the UK may have been considered enlightened for the time (especially contrasting the situation in the UK with that in the rest of the world), the proliferation of special schools also produced problematic issues for SEN policy that have endured over the last century. Stigma, equality of provision, and educational effectiveness were main concerns then and are still now. The first of these concerns was the perceived stigma that is often attached to being educated in a special school; such labels follow the individuals through their lives, reduce their opportunities, feed other people's prejudices, and limit their choices (Gray 2002). Indeed, the discriminatory and stigmatizing status of special schools is still keenly felt in this century, as seen in the following description of special education:

> Special schools have become the 21st Century gulags, where the collective fears of children who are seen as different is assuaged and their segregation from other children is reconstructed as 'special education' in a 'safe' environment. These children are in a very real sense 'the disappeared'—Joe Whittaker. (2001, p. 15).

An issue that is closely related to the potential stigmatizing aspects of placing children in segregated schools is whether different school provisions can ever, in practice, be equal or produce the possibility of equivalent outcomes. This is the aspect of the debate that underlies and prompts much of the "rights agenda" regarding inclusive education. This question was famously highlighted in the context of racial segregated education by the *Brown versus Board of Education* (1954) case that decided that the "separate but equal" doctrine, adopted in *Plessy versus Ferguson* (1896), had no place in the field of public education:

> Segregation of white and colored children in public schools has a detrimental effect upon the colored children…A sense of inferiority affects

> the motivation of a child to learn. Segregation with the sanction of law, therefore, has a tendency to [retard] the educational and mental development of negro children…We conclude that, in the field of public education, the doctrine of "separate but equal" has no place. Separate educational facilities are inherently unequal.

Similar debate has also been held over gender segregation, but this time over the issue of whether single-sex schools are beneficial. A review by Spielhofer et al. (2004) examined the claims that gender-segregated education reduces sexually stereotyped subject choices and is academically advantageous for girls. However, they found little evidence to demonstrate that this was the case and concluded that the research literature failed to provide convincing evidence that single-sex education has an impact on pupil performance.

It should be noted that in both cases of race- and gender-segregated education, the outcome of the debate was ultimately decided on the basis of whether the provision negatively or positively impacted the children. That is, it was argued on the basis of the educational effectiveness of the approach, and it is this latter issue that drove much of the move away from special education from the 1960s onwards.

From the establishment of special schools at the end of the nineteenth century to the 1960s, the positive impact of segregated schools on the progress of children with SEN was probably minimal. Certainly, in the context of ASD, Rutter et al. (1967) noted that special schools were little more than "holding bays" and did not improve the prognosis of individuals with ASD who were educated in those settings. In fact, the early reports on the prognosis for individuals with ASD were unremittingly bleak (see Howlin 1997; Levy and Perry 2011). For example, Rutter and Lockyer (1967; see also Lockyer and Rutter 1969; Rutter et al. 1967) found that over 50 % of these individuals were institutionalized 10 years after their diagnosis. Findings such as these prompted the drive to "normalization" in education with a hope of improving the prospects of these children (Nirje 1969), and, ultimately, to the view that "mainstreaming" children with SEN would facilitate their access to and participation in society. In the UK, this position was first crystallized in the 1970 Education Act, which removed the legal distinction between those who were educable (previously, the "feeble-minded") and those who were not educable (previously, the "educationally subnormal"), effectively entitling all children to education for the first time; this "integration" movement became one of the "central contemporary issues in special education" (Department of Education and Science 1978, p. 99).

For many, this Warnock report (Department of Education and Science 1978) which introduced the term "special educational needs" was the strongest articulation of the inclusive education movement, and has been described as a "major reformulation" of ideas about education and of the kind of provision to be made for pupils with SEN (see Wedell 2008). The Warnock report began the wholesale movement of pupils with SEN (including ASD) into mainstream schools, and had a major impact on legislation. The Education Act (1981) embedded these fundamental changes into the education system, and this drive towards mainstreaming all children with SEN was continued in the Education Act 2001, which legislated that: "The starting point is always that children who have statements will receive mainstream education" (Department of Education and Science 2001), and which might be considered the "high water mark" for the inclusion program in the UK.

The UK lead was later followed throughout the world; in particular, the UNESCO Salamanca Statement (1994) called for inclusion to be the norm because it combats discriminatory attitudes (Peck et al. 1992), creates welcoming communities (Bogdan and Taylor 1989; Murray-Seegert 1989), provides education for all, and improves efficiency and cost effectiveness of the entire education system (Affleck et al. 1988; Piuma 1989).

However, despite the initially positive reactions to the inclusion agenda, problems soon began to emerge with this as a wholesale educational policy. Many began to argue that trying to force all students into the inclusion mold was just as coercive and discriminatory as trying to force all students into the mold of a special education class or a residential institution (Kauffman 1989;

Mesibov 1990). Others suggested that this movement was little more than an exploitation of the child with SEN to fulfill a political abstract ideal and was pursued without regard for what is best for the child (see Lindsay 2003; Norwich 2005 for a discussion). For example, Bricker (1995) argued that the needs of the individual child should not be lost in a movement to advocate one type of placement over all others. While the proponents of inclusion argued that inclusive education is of value in itself, others noted that there are other important values with which a commitment to inclusion in mainstream schools may be in conflict such as a commitment to the best education for the individual (see Lindsay 2003; Norwich 2005). Moreover, it was not long before the fact that children with SEN are a very heterogeneous population came to be recognized as a barrier to a wholesale application of a mainstreaming policy (Cole et al. 1991; Mills et al. 1998). This was particularly true of those with ASD (see Lord and McGee 2001). Still others suggested that this "inclusive movement" might primarily be based on financial considerations, and on the assumption that placement of all children within mainstream settings would be cheaper (Kauffman 1989; Schopler 1990).

A lack of clarity in the definition of SEN and the absence of clear and consistent criteria regarding which children should have a statement led to further practical problems. Such problems include parents being unclear when they are entitled to provide extra help for their child, the respective roles of schools and local authorities not being defined, leaving room for conflict over who is responsible, and local education authorities having an open-ended commitment to an ill-defined group at a time when resources were limited (see Vevers 1992). Although the impact of such financial considerations cannot be underestimated, it was the educational effectiveness of the mainstreaming approach for children with SEN that ultimately led to serious questioning about this form of educational policy.

Advocates of inclusion had argued for the academic, prognostic, and social benefits that they expected the children to experience (Rutter et al. 1967; Stobart 1986; Warnock 2005). However, research noted that mainstreamed children with ASD and SEN in general often had very low social status and acceptance in the school community (Nabuzoka and Smith 1993), suggesting that, in practice, such children were physically present in the school but socially and emotionally excluded. The lack of substantial and consistent evidence for either the social or educational gains anticipated by the proponents of inclusion (Davis et al. 2004a) propelled many to say the research on the benefits of including a child with ASD in a mainstream school placement was inconclusive at best (Humphrey and Parkinson 2006) and more often was contraindicative (see sections below).

The growing weight of such evidence finally prompted the report by Warnock (2005) addressing the impact of educational policy for children with SEN; the report concluded that it was not working. The central debate contained in this report concerned whether mainstreamed children with SEN participate more if they are taught in mainstream schools than if they are taught in special schools. It concluded that they do not, and especially noted that the group with ASD was at particular risk from social exclusion.

In the light of these considerations, inclusion as a policy has been reassessed, so that it does not mean that all children should be educated in the same school, but rather they should be included within a common educational project: a view echoing that endorsed by the Tomlinson Committee (1996), where a mainstream placement was not thought of as a sufficient condition of inclusion. This report defined inclusion as a system, which is not necessarily an integrated setting.

The significance of the Tomlinson (1996) and Warnock (2005) reports was to illustrate that the concept of inclusion is primarily concerned with participation, and the prime objective of the rights argument can be achieved over a wide range of provisions that may go well beyond simple placement in mainstream schools. This shift challenged the initial, simple view of placing pupils with SEN into mainstream schools that were developed in accordance with the "normalization" agenda (Nirje 1969). This view still holds some sway; for example, Bailey (1998) suggested that inclusion focuses on three key aspects: (1) physically being in the same place, (2) doing the same educational activities as others, and (3) being socially accepted and feeling a sense of belonging. However, it is not regarded as central to the discussion. Booth (1996) criticized concepts of inclusion which describe such an ideal state or aim in an influential paper and instead suggested that inclusion be viewed as comprising: "two linked processes: …increasing the participation of students in the cultures and curricula of mainstream schools and communities…[and] reducing exclusion of students from mainstream cultures and communities" (p. 96). Thus the notion of inclusion shifted to a focus on schools responding to all pupils as individuals and restructuring the educational activities and provision to support those children (Sebba and Sachdev 1997).

It is this latter concept that is currently considered as inclusive. For example, Booth and Ainscow (2000) and Humphrey (2008) described inclusion as a "process" involving many things including the placement of pupils with SEN in mainstream schools, participation of all pupils in the curriculum and social life of mainstream schools, participation of all pupils in learning which leads to the highest possible level of achievement, and the participation of young people in the full range of social experiences and opportunities once they have left school. How this hierarchy of mainstream inclusion is achieved is, of course, of paramount importance. Norwich and Lewis (2005) note that any attempt at inclusion must not only involve recognition of the commonalities between the pupils attending that school, but also recognize group- and individual-specific needs, and provide support so that all pupils in the school can access the curriculum on offer.

The Impact of Mainstream Education on the Child with ASD

The preceding sections have highlighted some of the arguments regarding the education of children with ASD and SEN in mainstream school settings. As noted throughout the above discussion, the emerging themes regarding the aims of mainstream educational placements for children with ASD are not solely about "rights," but involve judgments regarding how effective that education is for the child with ASD (which may also, of course, be considered by some as an imperative in itself). From this debate, the key areas that have emerged in terms of the aims of inclusive education include the academic progress of the children, the social development of the children, and the impact of the school placement on the child's self-concept. However, the importance that should be attached to each of these issues in judging the success of a mainstream school placement for a child with ASD is not clear. Without the foundation of a definition of successful inclusion, neither evidence regarding effectiveness of mainstream education nor the practices that might best facilitate that practice can be developed.

In order to investigate these issues, Frederickson et al. (2004) sought to obtain staff views on what successful inclusion meant to them. It was hoped to investigate similarities and differences between the views of the staff groups centrally involved in implementing inclusion and to determine what skills they considered important in achieving successful inclusion. Any differences between different staff groups, such as mainstream and special school staff, in the rated importance of particular skills for successful inclusion, might reflect differences between the groups in their understanding of successful inclusion. The participants from different groups (mainstream school teachers, special school teachers, and educational psychologists) were presented with a hypothetical situation, in which six pupils, who used to attend a special school, were placed in a fictitious mainstream school. The participants were asked what information they would need in order to convince them that there has been a successful inclusion.

The results are shown in Table 22.3, which demonstrates two findings of importance. Firstly, the key areas regarded as representing successful inclusion in a mainstream school were academic progress, social progress, the child's views, happiness and discipline, and compliance with

Table 22.3 Percentage of responses suggesting important themes for judging the success of school inclusion reported by Frederickson et al. (2004)

	AOP	Att	CVH	PSH	DCB	LAP	SP	SSS	MM
Special	1	8	19	4	9	*25*	*21*	9	4
Primary	6	4	5	5	19	*20*	*28*	7	7
Secondary	4	6	13	3	14	*21*	*22*	12	5
Professional Support	5	4	16	4	4	*18*	25	17	7

AOP affects on other pupils and teachers, *Att* attendance, *CVH* child's views and happiness, *PSH* parental support and happiness, *DCB* disciplinary compliance and behavior, *LAP* learning and academic progress, *SP* social progress, *SSS* school support systems, *MM* methods and monitoring

school rules (see also Eldar et al. 2010). Secondly, the results also indicated differences between the groups of professionals, in that, while all agreed that academic and social progress were of paramount importance, mainstream teachers placed more emphasis on discipline, and special school teachers placed more weight on the child's happiness.

These findings corroborate the key issues that emerged from the above discussion of mainstream education for children with ASD and also allow focus on assessing the degree to which these aspects are achieved by children with ASD in mainstream setting. The following sections present an admittedly selective review concerning how mainstream education impacts these four areas for children with ASD, not with the aim of producing definitive evidence on this topic (there is none), but to highlight the problems encountered by children with ASD placed in mainstream schools, and also where support needs to be given in helping the child with ASD in a mainstream setting.

Academic Progress

A key issue in the argument for education in mainstream schools was that special schools did not produce the level of academic gains that should be expected in children with ASD (e.g., Lockyer and Rutter 1969). The contemporary situation with regard to this issue presents a mixed picture of results from rather few studies, almost all of which have significant flaws. In the broad area of intellectual disabilities, which is often comorbid with ASD (La Malfa et al. 2004), there have been a number of reviews of the impact of mainstream education on academic and intellectual development. Two of these reviews have been relatively wide ranging and have produced similar conclusions to one another (Freeman and Alkin 2000; Ruijs and Peetsma 2009); both suggest that mainstream placements offer some small advantages to children with mild intellectual disabilities compared to special educational placements, while both acknowledge that there are a number of studies that report no difference between these placements. In contrast, a review of children with behavioral problems often associated with ASD (Smith and Matson 2010) suggested that greater academic gains were made by children who displayed behavior problems in special schools (Schneider and Leroux 1994). The difference between the conclusions of this review and the reviews for learning difficulties may well be connected by the interference with academic progress produced by problem behaviors, especially in mainstream schools where discipline and compliance are seen as key to success (Frederickson et al. 2004). Given the association of ASD with behavior problems (see Smith and Matson 2010; Wacker et al. 2009), this may suggest an inherent problem for mainstream education.

Although relatively few in number, there are some studies that have observed the effects of inclusion in mainstream schools for children with ASD, but as for the broad intellectual disabilities literature, these studies have reported mixed results. One of the few studies to report an advantage for mainstream schools in terms of academic/intellectual gains was conducted by Kurth and

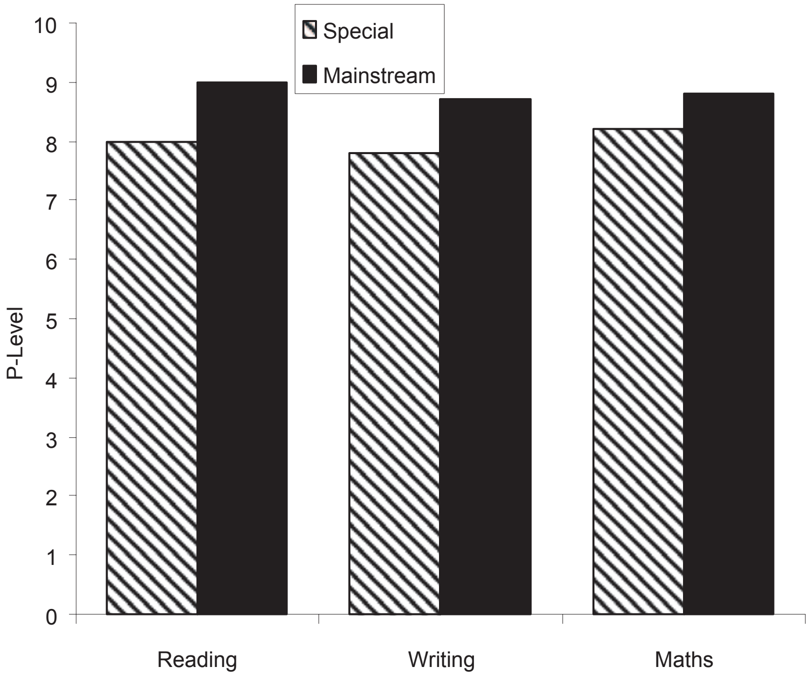


Fig. 22.2 Relationship between school placement and educational outcome (UK P-levels) as reported by Waddington and Reed (in press)

Mastergeorge (2010) on children aged between 12 and 14 years old who had continuously been in the same setting for some time. In this study, pupils who were in a mainstream setting for significant amounts of their school day (>80%) obtained higher scores on standardized tests of reasoning (including both abstract and inferential skills) than students who spent less than 50% of their school day in general education. However, the authors also noted that both sets of students did demonstrate gains in academic skills on these standardized measures.

In contrast, Harris et al. (1990) assessed increases in the ratio between developmental level and rate of language use in segregated versus integrated school provision. The results of this study found no differences between the developmental level and the rate of language use between students with ASD in the two settings, suggesting no difference in mainstream and special school in terms of the academic/educational advances for the children in those placements.

Similarly, Waddington and Reed (in press) assessed the records of 108 children with ASD (aged between 5 and 16 years) who were placed exclusively in either special or mainstream school. Particular focus was given to the pupil's achievement based on their national curriculum results, rather than on standardized tests, which may have a greater level of ecological validity. There were no differences in the autism severity or diagnoses between the pupils exclusively educated in mainstream schools and those educated in special schools (Fig. 22.2). Inspection of these data displayed in Fig. 22.2 reveals that the overall level of performance of the pupils was around the UK P-level 8 (a scale with 8 levels that is used for children working below that expected of children in the first year of primary school—usually 5–6 years old), which is much lower than would be expected for a cohort of this age. Further inspection shows that there was a slight advantage for pupils in the special placements over the mainstream schools in terms of national curriculum results. However, these differences were not great in magnitude and suggest no great impact on the academic achievement of the children.

Of course, there are many differences in the instructional methods that are adopted by mainstream and special education teachers (see Frederickson et al. 2010; Fuchs et al. 1992; Kauffman et al. 1985) that may account for the differences in the academic outcomes noted for each provision. For example, class sizes in special schools are typically smaller than those in mainstream classrooms (Office of Special Education Programs 1994; Reed et al. 2011). Smaller teacher-to-student ratios may lead to more individualized teaching that may foster children's performance (Hocutt 1996). Moreover, the curriculum in special schools tends to focus more on functional and daily living skills, and they work at a slower pace (Gersten and Woodward 1999). Any one of these differences may be responsible for the differences, or lack of difference between the outcomes from the schools. However, the methodology employed in a study reported by Panerai et al. (2009) partially addresses this issue. In this report, the progress of children with ASD, as measured on a test of developmental level, was compared across mainstream and special schools that were employing the same teaching technique (Treatment and Education of Autistic and related Communication handicapped Children; TEACCH). The academic/intellectual outcomes were virtually identical in these two groups and were higher than those noted in a mainstream class lacking this structured teaching approach.

The pattern of results reported above suggests that it is not necessarily the core ASD symptoms (see also Eaves and Ho 1997) nor the intellectual functioning of the children (cf. Freeman and Alkin 2000; Ruijs and Peetsma 2009) that impact their academic development in mainstream school. However, one factor that may determine academic success in mainstream schools could be the level of disruptive behavior emitted by the children with ASD (see also Kauffman et al. 1985; Kupersmidt and DeRosier 2004). In most studies that examined impact of mainstream versus special schools, the children have been included in the school for some time, suggesting that these are the pupils who are not emitting externalizing behaviors (as children with ASD who do emit externalizing behaviors are often excluded from such settings). One of the more negative results was reported by Ashburner et al. (2010), who found that teachers rated 54 % of the children with ASD included in their mainstream classrooms as underachieving, relative to their ability. This was not based on objective measures but rather by teacher perception; these children were also noted to emit high levels of disruptive behavior and to experience difficulty with the noise and class transitions of a mainstream school. This latter finding is in line with the perceptions of teachers regarding factors promoting successful mainstream inclusion (Frederickson et al. 2004).

In summary, there is no great reason to suppose that mainstream education will necessarily produce greater academic gains than placement in special schools. These mixed results and difficulties in controlling these studies tightly complicate the interpretation of this set of results. However, it might be suggested that those with lower intellectual functioning probably fare slightly better in special schools (Waddington and Reed in press), but those with higher intellectual functioning may well progress better in mainstream schools (Ruijs and Peetsma 2009). However, there are issues for those with ASD who do have higher intellectual functioning that may mitigate the positive impact of mainstream schools on their academic progress. These issues include the interaction between any perceptual sensitivities and the noisy environment of the school (Ashburner et al. 2010), the teaching style adopted in mainstream classes (Panerai et al. 2009), their levels of disruptive behavior (Kupersmidt and DeRosier 2004), and the teacher perceptions (Ashburner et al. 2010). Thus, in terms of academic progress, the safest conclusion is that this will be a product of the interaction between the individual and the school, and not simply a function of school placement.

Social Progress

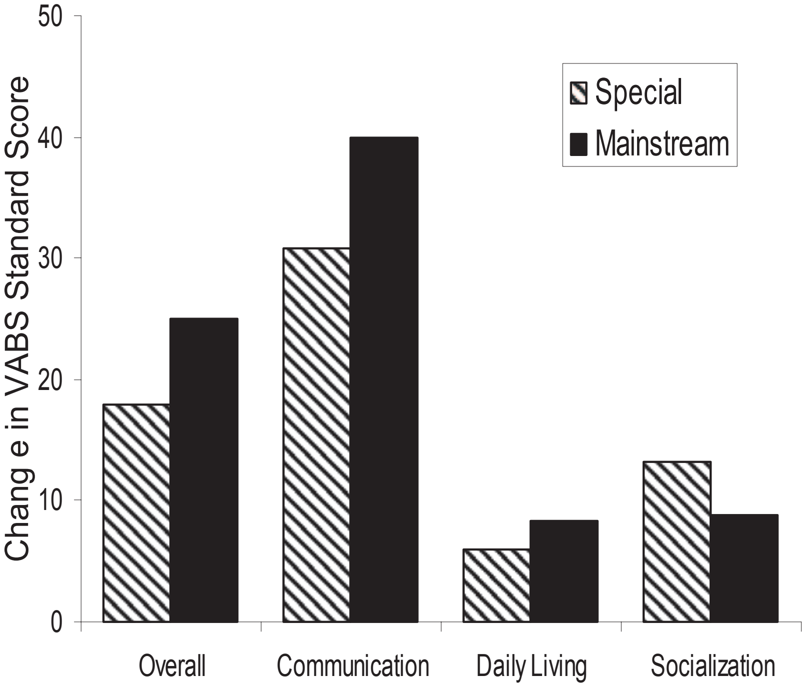
The major reason put forward by proponents of inclusive education for placing children with SEN in mainstream schools is the assumed impact of a mainstream placement on their social skills (see Connor 2000; Harris and Handleman 1997). Indeed, in terms of the general population of children with SEN, there may be some evidence to support this position. McGregor and Vogelsberg (1998) performed a review of the literature on SEN inclusion in mainstream and concluded that mainstream education is correlated with better social interaction and communication skills. Baker et al. (1994), in another review, noted small-to-medium-sized positive effects on social indices. In a single study, Buckley et al. (2006) noted strong gains for children with Down syndrome when they were included in mainstream schools. However, as Kurth and Mastergeorge (2010) have noted, a great deal of this work has been conducted on children with SEN whose primary deficits are not in the social area, as they are in ASD. It is well established that participation in social activities is particularly restricted in children and adults with ASD, and this may make generalization from the results obtained in the SEN literature to children with ASD difficult (Hilton et al. 2008; Knight et al. 2009; Orsmond et al. 2004).

The situation with regard to the effects of mainstream placements on the social progress of children with ASD is variable, with a preponderance of the evidence suggesting that problems can emerge in this domain from unmanaged inclusive programs. On the positive side, Strain (1983) focused on children with ASD in preschool and primary school and found that those children in mainstream schools exhibited more pro-social behaviors than their special school peers. Similarly, Buysse and Bailey (1993) documented greater improvements in social skills (defined as social behavior and play skills) for children with ASD in inclusive settings compared to segregated school settings. However, it is also important to be somewhat wary of accepting such data on face value as indicative of greater social progress. Boutot and Bryant (2005) suggested that ten pupils with ASD placed in a mainstream school were as “accepted,” “visible,” and “associated with peer groups” as those without disabilities in those settings. Unfortunately, inspection of these data show that, while there were indeed no statistical differences between the groups on all measures, the children with ASD performed worse than their peers; for example, while 70 % of the children with ASD were associated with a social network, 83 % of their typically developing peers were associated; the relatively small sample makes interpretation of the statistical significance difficult in practical terms.

In contrast to these positive results concerning social progress, several other studies have shown no such pattern of gains for children with ASD educated in mainstream placements (e.g., Durbach and Pence 1991; Harris et al. 1990; Reed et al. 2011). For example, Reed et al. (2011) assessed 54 children with ASD attending mainstream school and 86 children with ASD attending a special school. The children in the two groups were matched in terms of their age, gender, and the severity of autism symptoms. They were assessed at the start of the school year and then again at the end of the school year using the Vineland Adaptive Behavior scale, which includes measures of social and communication behaviors. The study found that both groups made similar improvements (Fig. 22.3).

Of potentially critical importance among these findings are a series of studies that have highlighted the social exclusion often suffered by children with ASD in mainstream school settings, often making their putative inclusive education a burden, rather than a benefit, for them (see Mesibov 1990). For example, Koster et al. (2010) found that children with SEN (including those with ASD) reported having fewer friendships with children in mainstream placements than typically developing peers (see also Cairns and Cairns 1994). A key question with respect to these data, however, is how many friends does it take to represent social progress? Perhaps more worryingly, Humphrey and Symes (2010; see also Ashburner et al. 2008) found that children with ASD reported more social rejection and lower acceptance in a mainstream school than both other SEN-included children (dyslexia) and a matched typically developing group (see also Koster et al. 2010). In fact, several authors have suggested that social isolation and loneliness are more characteristic of the child with ASD in the mainstream school than enhanced social interaction (e.g., Bauminger and Kasari 2000; Knight et al. 2009; Ochs et al. 2001), and, at the extreme, levels of bullying are particularly high for these pupils (Attwood 2007). Similar findings to these are often reported from the perspective of the child with ASD in many qualitative reports (e.g., Browning et al. 2009; Humphrey and Lewis 2008).

Fig. 22.3 Improvement in standardized scores of the Vineland Adaptive Behavior Scales over 9 months in school placements as reported by Reed et al. (2011)



The level of social isolation and social exclusion experienced by children with ASD in mainstream schools can lead to mental health problems (Barnhill and Myles 2001), especially around the time of transition to secondary education (Ghaziuddin and Greden 1998) when social comparison becomes more of an issue (Bellini 2006; Humphrey and Lewis 2008). This is more of an issue with higher functioning children with ASD or those with Asperger's disorder (Ghaziuddin and Greden 1998). However, as these are the very sorts of children with ASD who are likely to be included (see Buysse et al. 1994; Eaves and Ho 1997; Waddington and Reed in press), this aspect of education in a mainstream setting remains a serious problem.

The theoretical basis of expecting inclusion to promote social skills was based on the notion that children would model from their typically developing peers, and thus, acquire appropriate social behavior (see Boutot and Bryant 2005). In unmanaged mainstream placements, these suggestions runs into three problems that may explain the relative lack of success in this aspect of inclusive education: (1) It has long been established that children with ASD have deficits in their ability to model and imitate without special training (Rogers and Pennington 1991), (2) it has similarly long been established that imitation learning is better when the model of the behavior is perceived as similar to the observer (DiSalvo and Oswald 2002), familiar to the subject (Birch 1980), or socially agreeable rather than dominating (Marinho 1940). This suggests that unsupervised modeling may work better from other children with similar SEN problems than from typically developing peers. This view is consistent with findings reported by Osborne and Reed (2011) that children with ASD perform better in mainstream when there are more children with SEN in the school, and (3) if modeling were to occur, then there is little evidence that peers will spontaneously model strong pro-social behaviors (Attwood 2007; Humphrey and Symes 2010).

Thus, the evidence in relation to the effects and experiences of a child with ASD in the mainstream setting with regard to social progress is mixed, but with the strong suggestion that social progress will not spontaneously occur by mere placement in a mainstream setting. However, having presented this rather negative conclusion, it should be noted that many of these data are taken from psychometric assessments of social interactions and functioning, and not from actual classroom observation. This important gap in the literature will need to be filled prior to stronger conclusion being drawn in this area

Child Views and Happiness

The issue of whether a mainstream placement improves the child's psychological state including their self-concept is a rather fraught and complex area. Indeed, once included in a mainstream school, the views of the parents, teachers, and of the children themselves are often self-contradictory with respect to the impact of that placement on the child's psychological state. Moreover, there are many issues related to the measurement of this particular aspect of a child's development that are not easily resolved (see Koster et al. 2010).

As discussed above, there is still a widespread view that education in special provision is stigmatizing (see Gray 2002; Whittaker 2001). This negative perception extends not only to the future prospects of the child, but also to the view that such a placement has on the child's self-perception (Schneider and Leroux 1994). This was one of the key issues in deciding the judgment in *Brown versus Board of Education* (1954). In fact, when asked a simple question, a majority of parents of children with ASD want a mainstream placement for their child, not least as they believe that it will help their child develop a stronger self-concept (see Barnard et al. 2000; Resch et al. 2010). Indeed, child-related stress reported by parents decreased after their toddlers had been placed in mainstream education (Baker-Ericzn et al. 2005).

However, this rather broad characterization of parental views about the positive aspects of inclusion obscures a wide range of opinion with respect to the impacts of the placement on their child (cf. Leyser and Kirk 2004; Resch et al. 2010; Russell et al. 2012). For example, Leyser and Kirk (2004) noted that while parents expressed support for inclusion of their children with SEN in mainstream schools, this support was much more pronounced if their child had milder special needs, and most parents expressed worries about the deleterious impacts on the child's psychological state and self-concept caused by the potentially negative social reactions of their peers (see also above).

There have been surprisingly few studies of the impact of school inclusion on child depression and anxiety using typical psychometric tools, and most of the evidence stems from qualitative studies that have addressed the issue of pupil's views of mainstream placement (e.g., Bauminger and Kasari 2000; Browning et al. 2009; Humphrey and Lewis 2008; Ochs et al. 2001). These studies have noted that children with ASD often hold self-contradictory views about their mainstream education, premised on mutually exclusive values. In many cases, these views pivot around the potential dichotomy between wanting to be included in mainstream as they feel that this is somehow important (Straub 1995) and is a "privilege" for them (Humphrey and Lewis 2008), and the negative effects their treatment in that placement has on their own feelings (Bauminger and Kasari 2000; Ochs et al. 2001). Their views that a mainstream placement is to be valued are often premised on very negative perceptions regarding their own special needs (see Humphrey and Lewis 2008) that already stigmatize the children in addition to any special school placement. Such views will not be overcome by simple inclusion (see Nota et al. 2006, for a review). Additionally, many children with ASD included in mainstream schools express great concerns over the negative social reactions of their peers (Humphrey and Lewis 2008), and bullying (Browning et al. 2009) which strongly diminished their self-concept (see Bauminger and Kasari 2000). These negative impacts can lead to the later development of comorbid psychiatric problems (see Barnhill and Myles 2001; Ghaziuddin and Greden 1998). Thus, if "de-stigmatizing" is the goal of inclusive education for children with ASD, then there may be a heavy price to pay later in terms of depression and a reduced self-concept.

It has to be acknowledged that other than these qualitative studies, there is almost no evidence regarding how mainstream school impacts this aspect of children's development, and there are two major issues that need to be borne in mind when assessing these data. In terms of the qualitative data, these obviously are drawn from rather higher-functioning individuals with ASD (see Browning et al. 2009). In itself, this may tend to bias the samples surveyed, and even may highlight concerns over social interaction-induced problems to a greater extent than they are present for other included children who are not functioning at such a high level (although, as noted above, it is the higher functioning children who do tend to be included; Eaves and Ho 1997; Waddington and Reed in press). Moreover, there are concerns over the status of data that can be obtained through such self-report measures, which, in fairness, are the only way to estimate the child's views. As noted by several researchers (e.g., Cunningham and Glenn 2004; Koster et al. 2010), SEN pupils might have a positively distorted self-perception, overestimating their social status in the school. Although this may well be true, and such unrealistic evaluation may well cause problems in terms of the support that is offered or perceived as needed (Browning et al. 2009), it is less of an issue in terms of assessing the children's self-perception. If the included children are happy with the few friends that they may have, then that is all that is needed for an increase in their self-concept (and most people have an unrealistic estimation of their own ability, which stops depression setting in; see Alloy and Abramson 1979). Given all of these considerations, it may be safest to conclude that the impact of mainstream education is not dependent on just the mere fact of placement in this setting, as initially hoped for by many educators (Nirje 1969) and many parents (e.g., Resch et al. 2010), but it is largely dependent on the impact of the placement on a range of other aspects of the child's functioning and on their experience in that setting.

Behavior and Compliance

It is widely acknowledged that a key area that makes children with ASD challenging for their parents is the high level of externalizing behaviors that such children can display (see Eisenhower et al. 2005; Lecavalier et al. 2006; see Osborne and Reed 2009, for a review). Whether or not externalizing behaviors are considered as a core problem for ASD depends on which diagnostic classification system is followed (cf. DSM-IV-TR; ICD-10). Irrespective of this question, it is clear that parents report the externalizing problems to be more problematic than other facets of ASD by school age (Osborne and Reed 2009). Similarly, the presence of such behavioral problems rather than the child's views and happiness are thought to be key in defining a successful inclusion placement by mainstream educators (Eldar et al. 2010; Frederickson et al. 2004). Moreover, the statistics on school exclusion for children with ASD cited above (see Department for Education and Skills 2006) suggest that the aspect of behavior is the main instigator of school suspensions, and critically, of permanent school exclusions, which are associated with subsequent higher levels of criminal behavior and homelessness (Pirrie et al. 2011).

The literature devoted to this topic has suggested that the behavior problems experienced by children with ASD in a mainstream school are greater than those of their peers (Ashburner et al. 2010; Gadow et al. 2005; Macintosh and Dissanayake 2006; Reed et al. 2011). In these studies, both parent and teacher ratings of problem behaviors tend to be higher for children with ASD than for matched typically developing peers. Ashburner et al. (2010) compared teacher ratings of the problem behaviors emitted by pupils with an ASD diagnosis (broadly defined), who had an average IQ with those behaviors emitted by age- and gender-matched typically developing children educated in the same mainstream classrooms. The children with ASD were rated as having greater levels of behavioral and emotional problems than their typically developing peers. The study reported by Macintosh and Dissanayake (2006) compared parent- and teacher-rated behaviors of pupils with high-functioning autism and Asperger's disorder to those emitted by typically developing children matched for chronological and mental age. The groups with autism and Asperger's disorder did not display any differences from one another in terms of their problem behaviors based on either teacher or parent reports. However, both groups were rated as having social-skill deficits and greater numbers of problem behavior relative to typically developing children (Fig. 22.4).

Both of these studies (Ashburner et al. 2010; Macintosh and Dissanayake 2006) have suggested that behavioral problems are greater in children with ASD than in matched controls. Of course, there are several unresolved issues with respect to the impact of mainstream schools on problem behaviors of children with ASD, such as whether these behaviors are more pronounced in children with lower- or higher-functioning ASD. There are few studies with data bearing on this issue. Gadow et al. (2005) noted that pupils with higher-functioning ASD had more severe psychiatric symptoms, including oppositional defiant disorder, than lower-functioning pupils in mainstream settings. Osborne and Reed (2011) replicated these results comparing children with Asperger's disorder to children with ASD who were being educated in mainstream schools.

A second issue in regard to the impact of mainstream schools on behavioral problems of children with ASD is whether these children would have the same level of behavioral disorders in a special school setting. The evidence on this issue is very sparse with only one controlled study being conducted that has directly compared matched children with ASD in mainstream and special schools. In this study, also described above, Reed et al. (2011) measured the change in teacher-rated behavior problems in groups of matched children with higher-functioning ASD who attended either mainstream or special schools over the course of a year. The children made improvements in their behavior problems in both types of placements; however, those children in specialist provisions made greater improvements in area of conduct problems. Of course, there are many reasons why mainstream and special schools would differ from one another, and which explain these findings (see the section above), but the comparison of results reported for children undergoing the same curriculum (the Preschool Inventory of Repertoires for Kindergarten, PIRK®) in special or mainstream schools, reported by Waddington and Reed (2009; Studies 1 and 2), shows greater gains in terms of conduct disorders and hyperactivity, as measured by the teacher-rated Strengths and Difficulties Questionnaire, in the special schools compared to the mainstream schools. It should be noted that the group attending the special schools had more severe autism symptoms, and higher levels of behavior problems, at intake than the children in the mainstream group, although the latter difference had disappeared at the end of the year's exposure to the PIRK® curriculum.

Thus, a picture emerges with respect to behavior problems in which it is clear that children with ASD in mainstream schools exhibit a large number of externalizing behaviors, certainly a greater number than their typically developing peers, and which appear to be greater than matched groups in special educational settings. In part, these increased levels of externalizing behaviors may be a consequence of the limited repertoires of appropriate social language available to populations with ASD. This deficit appears to increase the likelihood that such children will engage in inappropriate off-task behaviors, stereotypy, or escape/avoidance behaviors (Carr and Durand 1985; Mirenda 1997). However, it may be important to note that these behavioral problems are almost always measured through teacher ratings, and such teacher ratings of the pupils' behaviors may be influenced by the teachers' perceptions of their own ability to deal with those behaviors (Avramidis et al. 2000; Reed and Osborne 2013). This latter perception of efficacy may well be weaker in mainstream schools than in special schools, causing some overestimation of the behavior problems in the former setting.

Factors Promoting Mainstream Success

The above section has highlighted, across a range of key areas of behaviors, that children with ASD included in mainstream schools do not necessarily perform any better than children with ASD

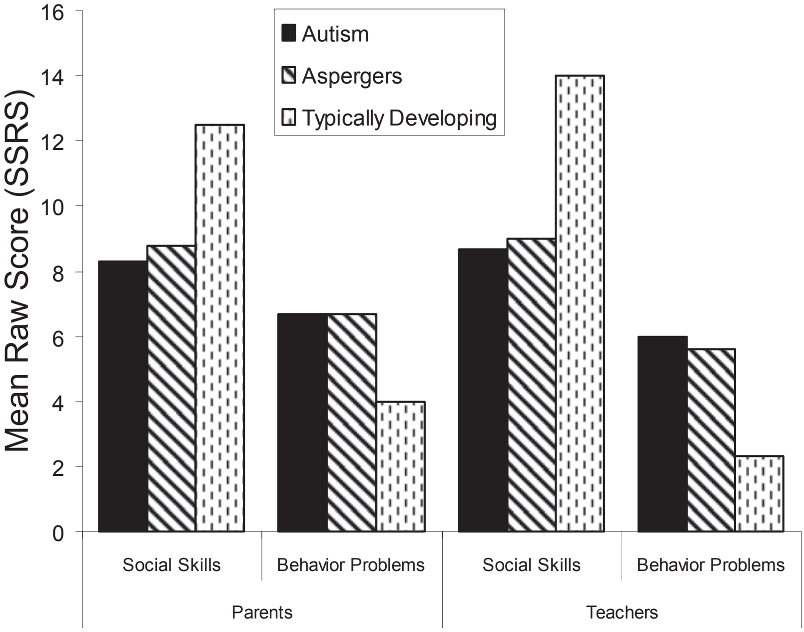


Fig. 22.4 Mean parents' and teachers' ratings of social skills and behavior problems using the social skills rating system in three groups of children at mainstream school calculated from the data as presented by Macintosh and Dissanayake (2006)

who are educated in special schools. In itself, this suggests that the mere placement in a mainstream school will not promote the performance of children with ASD, as initially hoped for by the "inclusive movement" (e.g., Nirje 1969; Warnock 1978). In fact, there are several instances where there are reasons to be highly concerned about inclusive placements being detrimental to the child (e.g., Humphrey and Symes 2010). Thus, ill-considered attempts at inclusion in mainstream school settings, based on rights- or de-stigmatizing-motivated agenda, may do lasting harm to children with ASD.

Although the results from studies based across many schools often show no particular advantage for mainstream settings, this grouped data also can obscure a set of important factors associated with improved chances of success in the mainstream for children with ASD. Of course, it is an uncertain point as to whether these "improved performances" reflect a mere return to the performance that would have been seen if the child had not been included in the first place. Nevertheless, the fact that there are such factors implies that these factors can be used to help develop a more successful approach to the mainstream education for children with ASD. The next section outlines some of what is known about these factors, and which should form the basis of mainstream practice for children with ASD.

Child Characteristics

Although an anathema to those on the extreme of the inclusive movement, it should be considered whether there are some children for whom inclusion may work, and some for whom it does not. In fact, there are a number of child characteristics that should be considered when planning a mainstream placement for a pupil with ASD. The de facto differential school placement based on the child characteristics (see Eaves and Ho 1997; Waddington and Reed in press) may indicate that this already be well established in practice (even in contravention of legislation; e.g., DFES 2001). It has already been noted that a mainstream placement is more likely if the child is higher functioning, both in terms of their autistic symptomatology (Waddington and Reed in press) and their IQ (Buysse et al. 1994; Eaves and Ho 1997), and if they are younger rather than older (Hocutt et al. 1984). Although it may well be that the increase in mainstream placements for all children with ASD is reducing these differences (see Frederickson et al. 2010). However, in addition to these characteristics, there are several factors that have emerged more recently in the literature that appear to predict successes and problems produced by mainstream placement. These factors relate to various aspects of the child's functioning; some of which could be considered as core symptoms of ASD, and some are not.

In terms of the child's ASD symptoms, there are differences in the reaction of a child to a mainstream placement that appear to correlate with their actual diagnosis (see Osborne and Reed 2011). While it is much more likely that a child with Asperger's disorder will be placed in a mainstream school than a child with autism (Waddington and Reed in press), there is a suggestion that it is the former group that are also more likely to show increased problems as a result of the placement. Prime among these problems are potential negative effects of the mainstream placement on their social and behavioral functioning (e.g., Gadow et al. 2005). Although it should be noted that it is not yet clear whether this finding is primarily related to the diagnosis of Asperger's disorder itself or to its correlates such as differences in IQ (Macintosh and Dissanayake 2006) and ability to make social comparisons (Bellini 2006; Humphrey and Lewis 2008).

Whatever the precise diagnosis, there are also indications that a key aspect predicting mainstream success is the child's social and communication abilities. A number of studies have shown greater mainstream success for children with greater social abilities compared to those with deficits in this area (McIntyre et al. 2006; Whitney et al. 1994); it is believed that these social skills may well impact their subsequent academic performance (see Kupersmidt and DeRosier 2004). These suggestions correspond to contemporary theoretical models, regarding emotional and social self-regulation, that imply early skills in social interactions, especially involving prosocial behaviors, are predictive of better school outcomes subsequently (Parker and Asher 1987). In children with intellectual disabilities, McIntyre et al. (2006) noted that preschool self-regulation (i.e., impulse inhibition) and social skills both predicted school adaptation, even when the level of IQ was controlled (see also Zingerevich and Lavesser 2009). This finding has been mirrored in children with ASD by Jones and Frederickson (2010), who found that if children's parents rated their social ability as low, this predicted a lower level of acceptance for those children in a mainstream school setting.

However, in addition to the core deficits of ASD such as social functioning, there are a range of problems that are often associated with children with ASD, which also impact the potential success of a mainstream school placement. Prime among these factors, as noted in the above section, is the presence of externalizing behaviors. These conduct problems reduce the likelihood of success of a mainstream placement (see Kauffman et al. 1987) and increase the likelihood of exclusion (Department for Education and Skills 2006).

Another symptom that is often associated with ASD and which may limit the chances of mainstream success is the presence of sensory processing problems (e.g., Baranek et al. 2006). Ashburner et al. (2008; see also Jasmin et al. 2009) found that sensory difficulties explained nearly half of the variance in academic performance for children with ASD in mainstream school settings; there being substantial negative relationships between both auditory filtering problems and tactile hypersensitivity and inattention problems, and also between movement sensitivity and oppositional behavior problems. Moreover, it is not only academic performance that may be correlated with perceptual sensitivities. Reynolds et al. (2011) noted that pupils with ASD who had greater sensory sensitivity also had lower social competence scores, and they suggested that this could negatively impact social participation. Certainly, Ashburner et al. (2010) have related these sensory problems to both conduct and social problems in school environments.

The presence of any of these negative predictors should raise concerns about the possibilities of simple inclusion in a mainstream school setting. If the child displays these characteristics, behaviors, or sensitivities, then it suggests that steps will need to be taken in order to help that child in the mainstream placement.

School Factors

A wide range of school factors may play a role in successful inclusion in a mainstream setting for children with ASD. Osborne and Reed (2011) reviewed such factors which include the number of other children with SEN included in the school, the size of the school (i.e., the number of pupils), and the size of the classes in which the pupils were placed. In this study, these school factors were related to progress in reducing behavior problems in secondary school-aged children with ASD in mainstream school over the course of a year.

The number of other SEN pupils was a positive factor in the mainstream school progress for children with autism, but not for those with Asperger's disorder. This suggests that a simple explanation of such findings, such as greater numbers of children being associated with greater school and teacher experience in dealing with children with SEN (see Osler and Osler 2002), cannot be a full account of these data, as this should have positively correlated with progress in both groups of children.

Both the size of the secondary school and the class size positively impacted pupils with autism. This positive relationship may appear counter-intuitive but corresponds to other work which has suggested that small class sizes are not necessarily optimal (Blatchford et al. 2007). Correspondingly, Cotton (1996) has presented data that suggest school size is inversely related to behavior problems; a finding that holds, at least, up to medium-sized schools (see Blatchford 2009; Newman et al. 2006, for reviews). In addition to improvements in behavior, Osborne and Reed (2011) noted the size of the school was correlated with increases in the level of self-reported school belonging in the children (Fig. 22.5).

These considerations stand in contrast to a range of other data that would seem to imply that aspects of a large mainstream school could be quite problematic for a child with ASD. Carrington and Graham (2001) demonstrated children with ASD may find large schools as stressful and anxiety-provoking places. This stress is often associated with large numbers of transitions between classes, especially in secondary schools (Myles and Simpson 1989), which may be problematic for children with ASD who prefer routines (Adreon and Stella 2001). Also, children with ASD who have sensory issues may find high levels of noise stressful.

There will be, doubtless, a range of further school factors that could be explored in this context. Some of these school factors will be known to individual authorities based on their experience with including children with ASD, but this evidence is not available. Whatever the school factor is (e.g., school size), it will certainly be mediated by a range of within-child factors (see Newman et al. 2006, for a review) and also by the procedures that are put in place by the school to limit the negative impact of these factors on the included children with ASD (e.g., Gibbons and Goins 2008). The full range of these interactions would be difficult to document, but the key point is that they will exist and will need consideration for each pupil with ASD and for each school, separately.

Teacher Factors

The level of training and experience that teachers in a mainstream school have regarding the potential problems that children with ASD included in their classrooms may experience is widely regarded as critical to the mainstream success of a child with ASD. Many teachers in mainstream schools report that they are ill prepared to deal with children with ASD (McGregor and Campbell 2001; Robertson et al. 2003); a finding neatly summed up in the title of a related report by Smith and Smith (2000): "I believe in inclusion, but…." In fact, Wishart and Manning (1996) found that while many teachers believed in the concept of inclusion of children with SEN in mainstream settings, only 13 % of these teachers believed it would work in practice, and only 6 % felt qualified to deal with a child with SEN in their classroom.

The above perceptions of teaching staff are supported by two important sets of findings. Firstly, teaching staff who have little training in

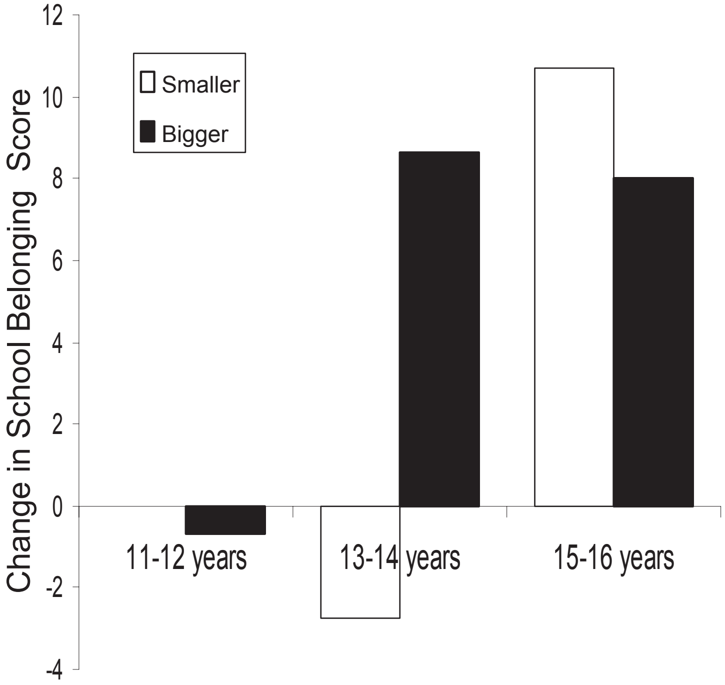


Fig. 22.5 Influence of pupil age and school size on the change in pupil's sense of school belonging over a 9 month period as reported by Osborne and Reed (2011)

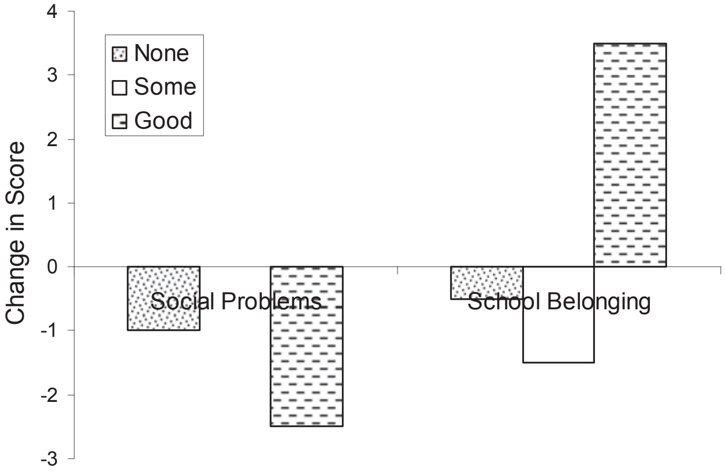
ASD (or SEN) are known to experience large amounts of stress and "occupational burnout" when placed in inclusive mainstream settings (Farber 1991; Reddy 2008). Secondly, it has been established that staff training regarding ASD leads to more informed teacher expectations about the prospects of the child (see Avramidis et al. 2000; Jindal-Snape et al. 2005; Waddington and Reed 2006). This can reduce unrealistic expectations of progress, often associated with perceptions of inclusive placements as failures (Frederickson et al. 2004). There is also a broader link between more accurate teacher expectations of children with ASD and increased success of those children in the school (Burack et al. 1997).

One of the more important aspects of increasing teacher knowledge is in allowing the development of a strong pupil–teacher relationship. As was discussed above, children with ASD often do not form many social relationships with typically developing peers in their classroom (e.g., Humphrey and Symes 2010). Given this, it is often the teacher–pupil relationship that becomes critical in the experience and success of a mainstream placement for a child with ASD (see Donnellan et al. 1984; Robertson et al. 2003). For example, Robertson et al. (2003) found that when teachers perceived their relationships with the included pupils to be positive, the behavioral problems exhibited by the child were reduced, and the children with ASD were better socially included in the classroom. Similarly, Osborne and Reed (2011) found that when teachers perceived their preparation for the inclusion of children with ASD to be good, this was associated with an improvement in the included pupils' social behaviors, and also with their sense of school belonging, measured over the year (Fig. 22.6).

Teaching Practices and Support

The actual teaching provisions that children with ASD receive in mainstream settings are highly diverse. These provisions vary with a large number of factors, such as the view of inclusion taken by the school, and the resources that the school has in order to deliver support to the included child with ASD. It has already been noted that when the same teaching practices are adopted in mainstream and special schools, differences in the progress of the pupils with ASD in these

Fig. 22.6 Change in pupils' teacher-rated social problems (Strengths and Difficulties Questionnaire) and school belonging scale scores over a school year as a function of self-rated teacher levels of training as reported by Osborne and Reed (2011)



different types of schools are minimized (e.g., Panerai et al. 2009; Reed et al. 2011). However, this equation of teaching provision usually means importing techniques, such as TEACCH or applied behavior analysis (ABA) methodology, developed for special school education, into the mainstream setting. Although this certainly may be an appropriate educational goal, the costs associated with this adoption of special school practice could be prohibitive when applied to the mainstream setting (see Schopler 1990).

Frederickson et al. (2010) have noted that for pupils with ASD included in a mainstream setting, most typically their support will take the form either of the provision of a dedicated support worker (e.g., McRobbie 2005), or the development of an ASD resource or unit (Hesmondhalgh and Breakey 2001). In terms of the success of these approaches, both have shown advantages, but both also have associated problems.

If support is provided in an ASD unit, the achievement of supported children may be perceived as greater by their parents (Barnard et al. 2000; Whitaker 2007), although there is little empirical evidence to show that this is, in fact, an accurate reflection of the impact. However, a consequence of this approach is that it may actually mean that fewer lessons are taken by the children with ASD with their mainstream peers (Frederickson et al. 2010). It is difficult to see how this practice could be considered as inclusion in the "participation" sense of the word outlined by Booth and Ainscow (2000). Moreover, under these circumstances, "acceptance" of the children with ASD by other pupils may also be a problem (cf. Giangreco et al. 1997; Humphrey 2008; Osborne and Reed 2011).

The alternative approach is to keep the child with ASD in the mainstream class, but offer support from a dedicated teaching assistant. The presence of such a teaching support worker certainly has been shown to help with the behavioral difficulties shown by children with ASD (Giangreco et al. 1997; Howes 2003; Osborne and Reed 2011). In contrast, this form of help for the child with ASD in the mainstream shows no evidence for improving the pro-social behaviors of the child (see Humphrey 2008; Osborne and Reed 2011). Conversely, help provided by a teaching support worker may actually isolate the pupil with ASD from other children, and reduce the level of pro-social behavior emitted by the child with ASD over time (see Osborne and Reed 2011). Additionally, children with ASD themselves sometimes voice concerns about the presence of a support worker in the classroom, in terms of this presence isolating them from their peers, and marking the differences more clearly (see Broer et al. 2005; Humphrey and Symes 2010). Such considerations demonstrate that the mere provision of resources for a pupil with ASD does not guarantee participation in the activities of the school, or acceptance by other children.

Table 22.4 Suggestions regarding practices that promote successful inclusion of children with ASD in mainstream schools

Delmolino and Harris (2011)	Frederickson et al. (2010)	Humphrey (2008)	Simpson et al. (2003)
Values and philosophy	ASD resources	Challenge stereotypes	Environmental manipulations
Evaluating quality	Training in ASD	Create order from chaos	Attitudinal and social support
Child and family characteristics and needs	Home-school communication	Promote peer understanding	Coordinated team commitment
Individual targets and plans		Develop social skills	Evaluation of practice
		Adapt academic subjects	Home-school collaboration
		Modify conversational language	

Supporting the ASD Child in the Mainstream

The above selective review has suggested that there are numerous barriers to the successful education of a child with ASD in a mainstream setting if there has not been adequate preparation of all people involved for that school placement. This literature also highlights the key areas that might present the major stumbling blocks to including such children in mainstream settings. Given all of this, the main issues to resolve in terms of helping the child with ASD in a mainstream school setting become: What can be done to support that placement, and what is known about the effectiveness of those suggestions? In fact, there have been a huge range of answers given to the former question, but in regard to the more important latter question, the simple answer is, rather depressingly: "precious little."

Even a brief summary of the literature contained in academic journals, and the suggestions contained on education authority websites, shows that there are a wide range of opinions offered on how to achieve successful inclusion in a mainstream school for a child with ASD. The more sensible of these suggestions (Table 22.4) regarding how to make mainstream education for children with ASD work (e.g., Delmolino and Harris 2011; Frederickson et al. 2010; Humphrey 2008; Simpson et al. 2003) are heavily based on the types of research-based consideration that are outlined above. These suggestions highlight the key areas where difficulties have been shown to arise, and propose solutions about how to tackle these potential problems. In particular, to enhance the education of children with ASD in mainstream schools, these suggestions stress the key need for prior preparation for mainstream placements that involve: (1) the teachers in the mainstream school, (2) the manner in which teaching is organized in the mainstream class, (3) the other children in the mainstream school, and (4) the child with ASD and their parents.

One way of summarizing these aspects of the support to be provided is that all are concerned with producing a better match between the abilities of the children with ASD and the environment in which they are placed. This objective is well reflected in a quote from a person with Asperger's disorder reported by Baron-Cohen (2003, p. 180): "We are fine if you put us in the right environment. When the person with Asperger's syndrome and the environment match, the problem goes away…When they do not match, we seem disabled." That is, interventions to aid mainstream placements are targeted at adapting that mainstream school environment to the child in order to more effectively contact that child's behaviors, and enhance their chances of success. This is the basis for most behavioral interventions for children with ASD (see Lovaas 1987).

However, it should be noted that although all of the above are good suggestions regarding the aspects of schools and personnel that need to be prepared prior to including a child with ASD, and, as far as they go, intervening along all of these fronts would certainly help to remediate some of the difficulties discussed earlier, the real difficulty comes when these suggestions are operationalized. While there is much in the view that changing your world will go a long way towards solving your problem, it is not exactly a recipe for effective action.

A key issue that requires urgent research concerns the myriad of specific suggestions that have been made in the literature regarding how to tackle these areas of potential difficulty in inclusive educational practice. These suggestions have not received even a small amount of the research that has gone into assessing early (or preschool) interventions for children with ASD. In fact, when they are surveyed, the specific suggestions and programs can present a rather daunting picture of the requirements for a potential intervention and may even be taken to reflect a rather piecemeal approach to this area of education. Given the increasingly important issue of educating children with ASD in mainstream settings (see Frederickson et al. 2010), this situation is unfortunate.

The situation is made more difficult and mainstream placements for children with ASD harder to implement once it is taken on board that these specific interventions must form part of an overall strategy to inclusive education for children with ASD, rather than mere “fire fighting.” As Koegel et al. (2011) have suggested, intervention programs for teaching children with ASD in the mainstream school setting must be both “comprehensive” and “individualized.” Of course, a council of perfection is not a great help, but anybody planning mainstream school placements for children with ASD will need to adopt an overall approach and philosophy to the placement. In addition, they will need to adopt a range of specific interventions to tackle certain key areas of potential difficulty; otherwise, as the above review has shown, these placements may be extremely stressful and even harmful for the child. The following sections outline the four key areas that will need to be tackled and make some suggestions as to the types of approaches that could be utilized in these contexts. Of course, this is not a comprehensive list of suggestions, but represents a starting point for developing thinking about this under-researched issue.

Preparing the Teachers

Many of the challenges facing an inclusive educational approach for children with ASD involve removing the stereotypes and raising the expectations of the teachers and staff regarding those children, and also regarding the teachers’ own competencies to teach such children. The single best way to achieve this goal is through the use of training to improve the teachers’ abilities and knowledge regarding children with ASD. A number of surveys have shown that more qualified staff feel more positive about the prospects of the children with ASD in the mainstream school as well as about their own abilities in managing the demands of having a child with an ASD in their classroom (see Hsien et al. 2009). As noted above, it has been shown that improving teacher confidence (Burack et al. 1997), and levels of training (Reed et al. 2011) promotes the success of inclusive mainstream placement for children with ASD. Given these findings regarding the importance of teacher training, the key issues resolve to determining what should be included in such training, and how should such training be delivered? There is no current consensus regarding these issues, but there are a number of reviews of the area in relation to ASD that offer several helpful suggestions (e.g., Koegel et al. 2011).

In terms of what should be included in any teacher training “package,” there are two main components that have been highlighted as important. The first component concerns promoting knowledge of the characteristic symptoms of ASD, explaining exactly what having ASD means for the child, and outlining the possible effects of these issues in the classroom. An important criticism of most mainstream placements that is made by parents, by children with ASD, and by teachers is that the teachers do not have an adequate understanding of the nature of ASD (e.g., Jindal-Snape et al. 2005; Waddington and Reed 2006). Some inclusive programs have attempted to overcome this problem by providing literature to teachers about ASD; even this simple approach has noted some improvements in those school placements as a consequence (e.g., Beecher and Darragh 2011). This should not be regarded as surprising, as many early intervention programs now include parent training to help them to understand the functioning of their child with ASD (e.g., Reed et al. 2012; Smith 2000; Whittingham et al. 2009).

The second overarching area to be covered in a training program for teachers are the skills that these teachers will need to help the children with ASD, including how to improve the social and communication skills of the children (see Koegel et al. 2011), as well as how to understand and manage their behaviors (e.g., Matson and Nebel-Schwalm 2007). That is, the mainstream teachers must be versed in some of the teaching techniques that are routinely employed in special educational settings (see Greer 1991, for discussion of this issue). If a putative teachers' curriculum for including children with ASD could be culled from these two broad areas, this would be a strong start in improving the success of mainstream placements. Precisely how this information should be delivered is still an issue of some practical difficulty, especially given the twin constraints of time and money facing most educational authorities. Koegel et al. (2011) outline three potential routes to delivering this type of information in reasonably cost-effective and sustainable manner: (a) brief in-service training courses, (b) video conferencing and coaching, and (c) pre-professional training.

In a survey of teachers' experiences of training for dealing with children with ASD, the first of these approaches (brief in-service training) was noted to be the most common (Morrier et al. 2011). However, this in-service training approach is not without its limitations. A number of studies have shown that short courses (of up to 5 days) can lead to an increase in the types of skills that may be needed when teaching children with ASD being displayed by the teachers on those courses (see Leblanc et al. 2009; Lerman et al. 2004; Lerman et al. 2008). In some cases, these skills, such as contingency management, prompting, and functional analysis, have been shown to persist and to generalize to the teacher's classroom interactions with other children. However, mere exposure to such a training program, without accurate feedback on actual teacher performance, preferably in situ, may not be effective. For example, Hall et al. (2010) found that teachers needed feedback on their application of the techniques that they learned in such training programs to maintain the gains that they reported as a result of attending the short course. There are major issues regarding how to train such skills, and whether such short courses can ever be a proper substitute for the use of qualified professionals (especially in the behavior analytic area, see Healy et al. 2009); but the literature appears to show that practically oriented and well-monitored short courses may offer much needed skills to teachers in the mainstream. The third area of training provision (pre-professional training) suggested by Koegel et al. (2011) may go some way to solve this issue, and would certainly involve including modules regarding ASD, and appropriate teaching practice, in pre-professional courses (i.e., teacher training courses). This issue has been discussed in detail by Scheuermann et al. (2003; see also Symon et al. 2009). Its implementation involves policy decisions about the training of teaching profession that are way beyond the scope of this chapter to discuss.

The remaining possibility for providing skills for teachers noted by Koegel et al. (2011) is through the use of technologies, such as the internet and videoconferencing. Both of these sources of information and training may provide quick access to skilled and experienced individuals, who could advise on many aspects of a child with ASD in a mainstream school setting. For example, Gibson et al. (2010) have documented and analyzed the use of videoconferencing for guiding interventions to aid children with ASD in mainstream schools. Similarly, Machalicek et al. (2010) have documented the use of this same technology in the area of developing a functional analysis of the factors controlling the behavior of a child with ASD. These technologies may offer a cost-effective solution to some of the training and support issues for specific problems. However, their full-scale effectiveness will need further investigation, as will their ability to promote a full understanding of the behaviors of a child with ASD.

Preparing the Teaching Strategies

The characteristics of a child with ASD mean that important adjustments will need to be made to the way that the teaching is conducted and structured within the mainstream school classroom. These teaching strategies must pay attention to several of the factors discussed above that may impact negatively on the progress of the child with ASD, such as reducing the number and level of disruptions in the teaching day experienced by the children, and capitalizing on the learning styles of the children with ASD. Of course, this is quite possibly true for any child. The importance of getting the teaching strategy correct is highlighted by the observation that it is the effectiveness of the type of teaching that is delivered, rather than the place in which it is delivered, that may count for more in promoting mainstream success for children with ASD (see Panerai et al. 2009).

As usual, there are a plethora of teaching strategies that have been described in the literature but which are not particularly well evaluated in this context. The impression, again, is of a rather disjointed field in rather desperate need of integration and classification of systems, although there are three rather helpful reviews that do begin to integrate and evaluate the literature with respect to teaching strategies (see Davis et al. 2004a; Delmolino and Harris 2011; Nind and Wearmouth 2006).

It appears that there are two main issues to be tackled in setting out an effective teaching program for children with ASD: firstly, to decide on an overall teaching strategy that will define the approach and the philosophy that will direct the teaching day (see Delmolino and Harris 2011), and secondly, to determine the particular tactics that will accomplish the goals for the needs of individual children within that framework (see Davis et al. 2004a; Nind and Wearmouth 2006). These correspond to the "comprehensive" and "individualized" approaches to including a child with ASD in a mainstream setting (Koegel et al. 2011).

With regard to the former overarching strategy, having a consistent approach to the teaching philosophy used to deliver the educational goals will both empower the teachers, by giving them clear guidance on what the approach actually should entail, and allow children with ASD to experience the consistency in their education that is sorely needed (see Delmolino and Harris 2011). The two overarching teaching approaches that appear to have the most research evidence in their support are the ABA (e.g., Greer et al. 2002) and TEACCH (Mesibov et al. 2005) systems. Although there are others which may work, they have not yet provided systematic evaluations of their effectiveness. Both ABA and TEACCH approaches to teaching share a number of common themes that are particularly important for the education of children with ASD. They both have a focus on the structure of the environment as a key determinant of learning, both examine the antecedents and consequences of behavior, and both focus strongly on the development of effective functional behaviors and communication skills. Importantly, both ABA and TEACCH approaches have high levels of validity in the eyes of all of the important stakeholders, such as the teachers, parents, and children (Delmolino and Harris 2011).

These two teaching approaches have considerable evidence in their favor in both special- and mainstream-school settings (see Greer et al. 2002; Makrygianni et al. 2011; Panerai et al. 2009). However, much more research is needed in this context, and it is completely unclear if one of these overarching strategies is more effective than the other, if one is more effective than another for particular groups of individuals, or, indeed, if this is even a sensible question to ask given the degree of commonality in the two approaches. That is, could the approaches be discriminated from one another with any degree of accuracy to an observer when they were put into practice in the classroom? Moreover, it may well be the case that it is the match between the philosophies of the teachers implementing the strategy and the strategy itself that is equally important in the successful delivery of programs (see Delmolino and Harris 2011; Jennett et al. 2003).

Unfortunately, despite such considerations, the available evidence and the high perceived validity of the approaches, it is far from clear

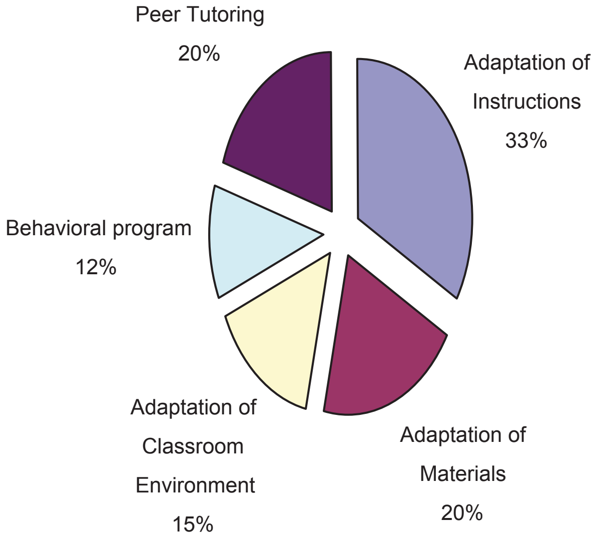


Fig. 22.7 The nature of the teaching approach adopted by mainstream classroom teachers for including children with ASD as reported by Nind and Wearmouth (2006)

that such overarching strategies are actually adopted in the mainstream education of children with ASD. For example, Nind and Wearmouth (2006) surveyed the teaching strategies that were employed in mainstream settings for educating children with ASD; they found that structuring the classroom environment (TEACCH) and behavioral approaches (ABA) were only adopted by 26 and 20 % of schools surveyed, respectively. In practice, most inclusive education programs for children with ASD relied on the adaptation of existing materials or on the utilization of peer tutoring for the child with ASD (Fig. 22.7).

In fact, considerations regarding the adoption of an overall teaching philosophy to guide education are often secondary to the development of particular tactics to teach particular skills. These tactics usually focus on adapting traditional techniques for use with children with ASD in order to focus on issues such as communication and language skills, cognition and learning, social-emotional development, and sensory and physical issues (see Davis et al. 2004b, for a scoping review). In their review of teaching practices for children with ASD, Davis et al. (2004a) concluded that the most commonly used teaching strategies for children with ASD were not really any different from those employed for children without an SEN, and could not be considered as forming a special set of strategies. Given that it is quite clear that there are significant and important differences between a child with ASD and their typically developing peers, this situation is unfortunate.

In fact, a key gap remaining in the literature is that there is very little evidence relating to the absolute or relative effectiveness of any of these teaching strategies in the context of ASD. There are, of course, a wide number of very well-documented ABA approaches to deal with each of the areas noted above by Davis et al. (2004a); that is, communication, learning, social-emotional development, and sensory-physical problems (see Reed 2009). A further reason to favor an approach based on an overarching philosophy, such as ABA or TEACCH, is that a key difference between such structured-teaching approaches and teaching approaches that are merely adapted from traditional strategies is that the former do not assume that learning is primarily a product of social interaction. Even if materials are adapted for children with ASD from those that are already utilized in the mainstream classroom, if those materials are based on common assumptions regarding social reciprocity and incidental learning in teaching, they may fail with the population with ASD. In fact, this assumption has been shown to be a key blockage in interaction between the pupil and teacher, when that pupil has ASD (see Tutt et al. 2006). It should also be remembered that, by their nature, structured teaching approaches also overcome such problems with more traditional teaching strategies.

A further difficulty in this area is that these well-documented overarching approaches for educating a child with ASD all stem from the special school context, while mainstream teachers typically prefer to adapt well-used techniques from the regular education context (see Nind and Wearmouth 2006). It is perhaps a moot point, given the low probability of it happening, as to whether the wholesale adoption of special school techniques into the mainstream school would make that context "mainstream." However, the partial adoption of such techniques is not without its problems. For example, Frederickson et al. (2010) have argued that over reliance on special school strategies merely for the children with ASD may reduce the inclusiveness of the setting for those children—marking the child out as different from the other children (see also Humphrey and Lewis 2008). Certainly, this is a paradoxical situation in which individualized instruction is thought to be a goal, and even a necessity, in the inclusive education of children with ASD (Koegel et al. 2011); however, separate teaching strategies being applied to different children may have unwanted social impacts for children with ASD (see Humphrey and Symes 2011; Osborne and Reed 2011). One solution has been suggested to make all of the mainstream school adapt these strategies developed in special educational contexts (Greer et al. 2002). There may be some merit to the argument based on the research data, but it certainly would be expensive in the short term, at least.

Preparing the Other Children

The issues of stigmatizing the child with ASD in the mainstream setting raised above links strongly to the most critical evidence against the use of mainstream placements for children with ASD. That is, the potentially negative impact on the social progress of the children (Bauminger and Kasari 2000; Humphrey and Lewis 2008) and ultimately, on their mental health (Barnhill and Myles 2001). These negative impacts arise mainly from the possibly negative interactions of the included child with ASD and their typically developing peers. Given all of this evidence, there is a very good reason to suggest that any planned mainstream placement involving children with ASD must include preparation and work with the other children in the school who may not initially understand the difficulties experienced by the child with ASD (see Ferraioli and Harris 2011; Simpson et al. 2003, for some discussion).

Frederickson and Furnham (1998; see also Jones and Frederickson 2010) have suggested that the quality of social contact will be inversely related to the "costs" involved in that contact (i.e., they have applied Social Exchange Theory to this context). If the child with ASD exhibits severe externalizing behaviors, these costs may be quite high for the other children, and these typically developing peers will not tend to seek out and engage with the child. Thus, there is good reason to assume that the other children will need to be taught skills in developing social relationships with children with ASD (see Straub 1995). In fact, the review of teaching strategies produced by Nind and Wearmouth (2006) suggests that this aspect of developing a mainstream school for a child with ASD is more advanced than other areas, with over a third of the programs involving some training for the other children.

While it is true that the greater the level of exposure to a group of children with SEN, the more positive is the attitude of others towards those children (Yazbeck et al. 2004), it is also true that this relationship is mediated by knowledge about those children with SEN (see Hsien et al. 2009). In fact, there are a number of approaches to facilitating the understanding of children with ASD that can be adopted in this context so as to allow exposure to the children with SEN to positively impact the attitudes of the other children (see Davis et al. 2004a; Nind and Wearmouth 2006, Rogers 2000, for reviews). Some form of social training that includes the typically developing children in the school would seem to be an essential aspect of successful inclusion in the mainstream class. A long-used approach to tackle this issue is to employ peer-mediated schemes to increase the social interaction between typically developing children and children with SEN (see McConnell 2002, for a review). In these schemes, typically developing children are taught to initiate and prolong social interactions with children with ASD. To this end, these social skills are initially practiced on adults in a role play situation. Once these skills are learned by the children, the typically developing peer tutors are prompted to apply these skills to children with ASD. Many studies have noted subsequent increases in the social interactions involving the included children with ASD (see Goldstein et al. 1992; Hoyson et al. 1984; Laushey and Heflin 2000).

Of course, these skills need further support and training to maintain and generalize, but there is a considerable literature outlining the optimal situation for this approach (see McConnell 2002). In general, there is evidence that skills dealing with the demands and challenges of interacting with children with SEN can be maintained and generalized. They can also be maintained in the absence of adult reinforcement, by the use of self-monitoring procedures (see Strain et al. 1994). While many of the studies focus on the impact on the child with ASD, there also is evidence to suggest that these schemes actually impact the behaviors and understanding of the typically developing peers. Peer tutors show greater levels of maintained friendships with children with ASD, as well as greater social skills and popularity in general (see Locke et al. 2012).

A similar approach to improving the understanding and abilities of typically developing children with respect to to-be-included children with ASD is to conduct social skills groups (see Kamps et al. 1994; Frederickson and Turner 2003). For example, Kalyva and Avramidis (2005) employed a “circle of friends” approach to develop social relationships between children with ASD and their typically developing peers. In this intervention, children with ASD had a circle of friends group for thirty minutes, on a weekly basis, for 3 months. These children had higher successful response and initiation rates immediately after the intervention and at a follow-up point than children in a control group. Although this was a very small-scale study, similar results were also noted by Frederickson and Turner (2003) in a larger study. Thus, there are a number of procedures that can be adopted to enhance the understanding and abilities of the typically developing children in the mainstream school prior to and during the inclusive placement of children with ASD in that school. These interventions may well be critical in ameliorating the otherwise negative impacts of such placements.

Preparing the Child with ASD and Their Family

The issues regarding preparing the child with ASD for the mainstream placement are fairly much coextensive with those concerning how to tackle the major areas of difficulty for the child with ASD: that is, how to improve language, social-communication skills, and reduce challenging behaviors. The literature on these topics is vast and beyond the scope of this chapter to discuss in any detail, but these issues can be noted in many of the chapters in this volume. There is little doubt that early intervention will certainly prepare the child with ASD with many of those pre-academic skills that will be required in mainstream.

There are the usual questions remaining about the best manner in which to enhance these skills, and this debate regarding the comparative merits of approaches such as ABA and special nursery placements has sparked much heat and, indeed, some light (e.g., Howard et al. 2005; Magiati et al. 2007; Reed et al. 2007). The position currently seems to be that most reports will accept that ABA is the most effective approach to develop intellectual, educational, and linguistic skills (see Makrygianni and Reed 2010, for a meta-analysis), but it is not exclusively effective (see Charman et al. 2004; Reed et al. 2007). The ABA approach may well offer its greatest relative impact for those children with greater autistic severity (Reed and Osborne 2012) and may well impact most strongly on behavioral and educational skills (Reed et al. 2007). However, there is some suggestion that approaches that educate the child in social settings, rather than in 1:1 settings, may improve the child’s social skills (see Reed

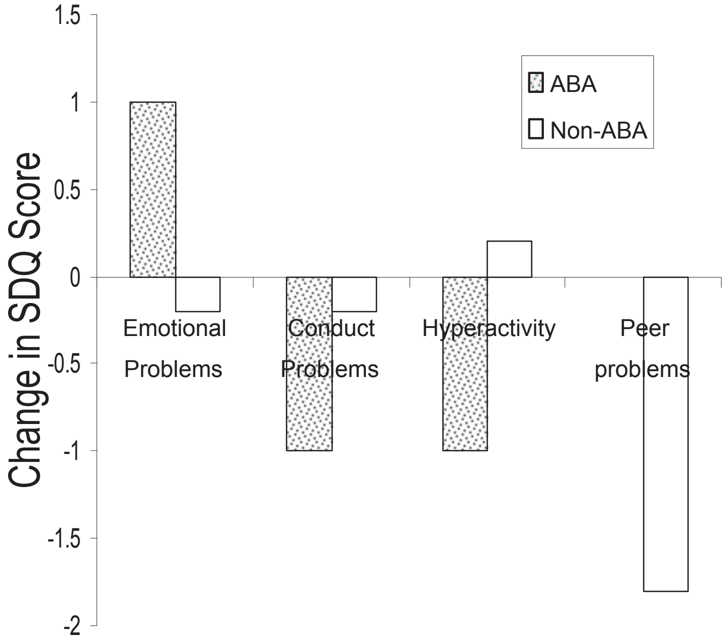


Fig. 22.8 Change in teacher-rated child problems over one school year following previous training on either an ABA or non-ABA intervention reported by Waddington and Reed (2009)—a decrease is an improvement

et al. 2007); this may well also apply to ABA approaches (Eldevik et al. 2012; but see Waddington and Reed 2009). The key question in this context remains whether it is more important to develop intellectual or social skills to facilitate subsequent mainstream functioning in children with ASD. Waddington and Reed (2009; cf. McGarrell et al. 2009) noted that children who had undergone ABA preschool training fared better at mainstream school in terms of their conduct, but less well in terms of their social and emotional functioning, than children who had attended special nursery schools (Fig. 22.8).

In addition to such concerns about how best to prepare the child with ASD for a placement in a mainstream class, there are a number of less well-documented areas that also need consideration. In particular, the role of the family in facilitating the success of any educational intervention for a child with ASD has been well documented (e.g., Osborne et al. 2008; Robbins et al. 1991). A few key parent factors that may facilitate the impact of education for children with ASD include the levels of parenting stress that are experienced (Osborne et al. 2008).

However, research has only begun to scratch the surface of the relationship between parent factors and educational success for their children. In terms of the parent-school relationship, the development of a positive relationship between the school and the parents of the included child is certainly associated with better outcomes for the child (see Christenson 2004; Osher and Osher 2002), and there are a number of practices that have been suggested as important in this regard (see Brookman-Frazee 2004; Koegel et al. 2009, for discussion). Some of these factors and suggestions regarding how to facilitate this aspect of preparation for a mainstream placement have suggested adopting: (1) a family-driven approach to the inclusive placement that stresses the acceptability of the school's approach to the family, and that also considers the impact of the school placement for the child with ASD on the entire family's quality of life (Christenson 2004), (2) developing a joint responsibility between the school and the family for the educational decisions that are taken for the child with ASD (Osher and Osher 2002), and (3) ensuring an ongoing communication between school and family (Adams and Christenson 2000; Koegel et al. 2009). As with the issues concerning the relationship of parent functioning to the educational outcomes for their children, quite how these factors can be established has not been the subject of a great deal of research, and a key difficulty in this respect is the nebulousness of some of the concepts involved. Nevertheless, this remains an area in urgent need of investigation.

Summary

The current chapter has attempted to outline, admittedly very broadly, the current state of knowledge regarding the education of a child with ASD in a mainstream classroom. As with many other reviews of this area, it is difficult not to conclude that the problems of this inclusive approach may well outweigh the benefits. It cannot be stated with any conviction that mainstream education will be appropriate for all children with ASD. Indeed, in many cases, mainstream education may be against the child's best interests and may be motivated by either misplaced political or economic imperatives. If the motivation behind mainstreaming a child with ASD is purely political in nature, then the group imposing that view needs to be very careful that they are not imposing their set of values on others to the detriment of those to whom it is being done. If the motivation behind inclusion is economic, then this view may well be deluded as either it will be very expensive to produce effective strategies for the appropriate mainstream education of children with ASD or even more expensive to sort out the problems that the experience has left the child with later in life. The discussion of the context to the "inclusive" education movement served to highlight the different goals that this policy could have and, in this light, a very cautious approach to the wholesale implementation of such a policy is urged.

The impacts of mainstream education on the child with ASD in terms of the child's likely academic and social progress and the impacts of such placements on their psychological and behavioral functioning suggest that there is little evidence to support the view that mainstream placements are inherently superior. In fact, there is much evidence that poorly managed mainstream placements can be harmful. A range of factors that impact the success of mainstream placements were discussed, including the characteristics of the child, the school, the teachers, and their teaching practices. Any program of inclusive education that involves placement of children with ASD in mainstream settings will have to involve the adoption of a range of interventions to support the child, the teachers, the school, and the family in delivering that mainstream placement. It can be concluded that, while there are strategies for helping the placement of children with ASD in mainstream schools, these schools may not always be the best place to serve the needs of these children and their right to an effective education, especially as these children often perform and develop just as effectively in a special school environment where the resources to help them already exist.

To reiterate the quote from Horace Mann (1848) employed at the start of this chapter, education is concerned with equalizing the opportunities for all by providing a person with the skills and strength to achieve what they can achieve and to allow them to protect themselves from being imposed upon by others. The imposition of one set of values on another set of people, especially values that are of dubious value to those people on which they are being imposed, certainly falls outside that definition. The inclusion of all individuals in society is a goal of any civilized country; it is clear that this will not be achieved through ill-prepared movement of all into the same educational settings. The education of a child with ASD in any setting, let alone in a mainstream school, is a procedure that requires a specialized teaching process, and the current review has highlighted some of those areas in which preparation is necessary.

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Controversial Treatments for Autism Spectrum Disorders

23

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Keywords

Evidence-based practice · Empirically validated treatment · Alternative medicine

Autism spectrum disorders (ASD) are a group of neurodevelopmental disorders that share overlapping diagnostic criteria ranging in symptom severity. Currently, diagnoses of ASD are based on a triad of observable behaviors including impairments in communication, impairments in socialization, and repetitive behaviors and restricted interests. And, while the prevalence of the disorders comprising the spectrum continues to be on the rise (Rice et al. 2010; Sun and Allison 2010), the etiology of ASD remains relatively unknown. More concerning for parents of children diagnosed with an ASD is that there is no known cure. As a result, parents are desperate to implement any treatments that have reported effectiveness (Elder et al. 2006), even if reports are anecdotal.

What is agreed upon by researchers, clinicians, and parents alike is that early intervention is imperative for children diagnosed with an ASD. And, research has provided support for early intervention (Hayward et al. 2009). However, what is not yet consistently practiced across professionals is the promotion of only treatments that have empirical support. Unfortunately, alternative treatments that lack evidence of efficacy are being utilized for children diagnosed on the spectrum. For example, researchers have reported that over 30 % of study participants diagnosed with an ASD were being treated with complimentary or alternative methods or medicine (Green et al. 2006; Levy et al. 2003), and these percentages are concerning. The unique and idiosyncratic characteristics associated with ASD, irregular and occasionally advanced skills (e.g., splinter skills or savant abilities), heightened susceptibility of having associated behavioral or psychiatric conditions, increased prevalence of those being diagnosed as having autism, and the permanent (or life-long) nature of the disorder are a few of the factors that have fueled debate about which treatment and intervention choices are most likely to yield favorable outcomes (Pavone and Ruggieri 2005). Due to these reasons, the field of ASD has the distinction of being a boon for numerous popular, but often unsubstantiated, treatment options. Autism is, in essence, a “fad magnet.” These highly controversial treatments and intervention strategies are largely invalidated and offer little in the way of empirical data to support the efficacy of the therapy tactics, even when extraordinary and incomparable results are promised.

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Fortunately, empirically supported treatments exist to remediate core and associated symptoms of ASD. However, what constitutes an empirically supported treatment? The Task Force on Promotion and Dissemination of Psychological Procedures (1995) outlined criteria to determine what constitutes a treatment as well established. These criteria include that at a minimum, results from two studies indicate that the treatment under evaluation is superior to an established treatment or superior to a placebo, and the studies need to be conducted by at least two independent researchers. Alternatively, several single-subject design studies that show a treatment is superior to a placebo or other treatment could also ascertain a treatment as well established. Alternative or fad therapies, then, refer to treatments that lack sufficient empirical support to be considered well established. Tuzikow and Holburn (2011) provided the following definition of a fad treatment for ASD: "a technique or approach that is overpromoted in relation to its credibility" (p. 1). The treatments covered in this chapter fall into the latter category because they lack the empirical support required to validate efficacy.

Without scientific support, why then are these alternative treatments being implemented? Tuzikow and Holburn (2011) identified likely groups of promoters of alternative treatments including parents and semiprofessional practitioners. Parents of children with autism are confronted with raising their child who has been identified as having a life-long disability for which there is, at this time, no clear explanation why it manifests nor is there an accepted course of treatment. The stress of having a child with ASD or other developmental disability can lead to frustration and disappointment for the parent (Pavone and Ruggieri 2005; Romanczyk et al. 2003). As a result, parents may seek out many different treatment options out of desperation to help their child, are trusting of professionals promoting alternative treatments, and may lack the knowledge necessary to understand what constitutes a supported treatment (Metz et al. 2004). Thus, it is imperative that professionals promote treatments with supporting empirical evidence and also provide the parents with the knowledge necessary to know what questions to ask when considering a specific treatment for their child. However, even if parents have information regarding which treatments are empirically supported, they may have a sense of urgency to find an effective treatment quickly (Levy and Hyman 2005); therefore, the length of time studies take to be conducted, published, and disseminated may be too far down the road. Parents have also reported trying numerous different strategies at one time to treat symptoms of ASD, which helps to illustrate their need to find an effective treatment quickly. For example, Green et al. (2006) conducted a survey of 111 different treatments used by parents of children with ASD. Results of the survey indicated that on average, parents were presently utilizing seven different treatments for their children (Green et al. 2006). How then would anyone be able to discern which of the seven treatments is responsible for reduced symptomatology, if any at all?

In regards to semiprofessionals, they may not demonstrate the expertise and clinical competence at the same level as professionals who were trained as scientific practitioners. More specifically, they may lack the training necessary to identify research evidence to support or reject the use of a particular treatment (Task Force on Promotion and Dissemination of Psychological Procedures 1995). Furthermore, research has shown that these practitioners value colleague consultation, their own prior experience, how-to-books, and workshops (Blanton 2000). Of concern is that they place a greater value on the aforementioned than on scientific research articles (Blanton 2000). Given this information, it is not surprising then that some semiprofessionals would promote alternative therapies for the treatment of ASD.

So, even though alternative treatments are not empirically supported, what is the harm in using them to treat symptoms of ASD? First, utilizing these unsupported treatments can be a waste of the families' time, money, and may provide families with a sense of false hope (Zane et al. 2009). Secondly, and more problematic is that some adverse side effects have been reported following the utilization of these various fad therapies.

Therefore, the clinical safety of all alternative treatments should be assessed prior to use (Pavone and Ruggieri 2005). And, third, time spent implementing an unsupported treatment could have been better spent implementing a supported treatment with documented success for treating core and associated symptoms of ASD.

Controversial and Alternative Treatments

Gluten-Free and Casein-Free Diet (GFCF)

Gluten is a protein found in foods such as wheat, barley, rye, and oats; and casein is a protein found in dairy products. This dietary intervention involves the total elimination of these proteins in the diet. One of the uses of the GFCF diet is to treat symptoms of ASD, and it was implemented in response to one of the etiological theories of ASD, the opioid excess theory (Shattock and Whiteley 2002). The opioid excess theory, first proposed in 1979 (c.f. Panksepp 1979), postulates that symptoms of ASD result from an overactivity of the opioid system (1979). Panksepp (1979) reported that injecting low doses of morphine into animals produced symptoms similar to those observed in individuals with autism (e.g., no need for social relationships, unusual motor movements). So, what then causes the overactivity of the opioid system? It has been further hypothesized that ASD is caused from peptides derived from incompletely digested proteins (i.e., gluten and casein). These peptides pass through the blood-brain barrier and attach to the opioid receptors (Mulloy et al. 2010). Thus, the brain treats the proteins like opiate-type chemicals.

One of the first studies to address the abnormal production/absorption of peptides in those with ASD was conducted by Cade et al. (1999). Cade and colleagues examined the effects of the GFCF diet on the following symptoms: eye contact, social isolation, mutism, learning skills, hyperactivity, stereotypical activity, hygiene, panic attacks, and self-mutilation. A significant improvement was observed in all areas investigated within 3 months of initiating the diet. Additionally, these gains were maintained through a 12-month follow-up. Although Cade and colleagues reported that the GFCF diet is beneficial in treating symptoms of ASD, the study was not without limitations. Most notable is that ratings of symptoms of ASD were completed by both parents and physicians. While inter-observer agreement between the raters was calculated to be greater than 90 %, the raters were not blind to the treatment. Thus, pre- and posttreatment data were not objectively collected and could have been influenced by opinions and feelings. Also, no control/placebo group was employed for comparison purposes in an effort to rule out threats to internal validity. Furthermore, symptoms of ASD were simply listed and rated on a Likert type scale. The results would have been strengthened if a psychometrically investigated measure was utilized to assess symptoms of ASD.

Since the early studies conducted on the GFCF diet for the treatment of ASD symptomatology, many other studies have been conducted. Fortunately, reviews of these studies have also been completed. For example, Mulloy and colleagues conducted a review of 14 published studies that examined the usefulness of the GFCF diet on symptoms of ASD (2010). Results of the 14 studies were variable in their support for the GFCF diet to treat ASD. However, the results of Mulloy and colleagues review indicated that the diet does not ameliorate symptoms of ASD and that it lacks scientific support. Not only did Malloy and colleagues find a lack of empirical support for the diet, the results of their review also provided evidence against the opioid excess theory as an etiology of ASD. In addition, they identified that the studies reviewed in their research lacked experimental design, did not utilize control groups for comparison, implemented the diet for very short intervals, did not utilize inter-observer agreement, and did not use raters who were blind to treatment (Mulloy et al. 2010).

Studies that have been conducted with scientific rigor have concluded that the GFCF diet is ineffective for the treatment of ASD. For example, Elder et al. (2006) conducted a double-blind investigation of 15 children diagnosed with an ASD who were randomly assigned to a control group or a GFCF diet group. Symptoms of ASD were assessed through the use of the Childhood Autism Rating Scale (CARS) at baseline, and weeks 6 and 12 of the intervention. No significant differences emerged when assessing symptoms using the CARS. Additionally, the researchers reported nonsignificant differences in the urinary peptide levels of both casein and of gluten. Interestingly, even though no benefits of the GFCF diet were reported, a large percentage of parents decided to keep their child on the diet following the cessation of the study (Elder et al. 2006).

As evident in the literature, the GFCF diet has yielded some promising results, but these results have emerged from studies that lack sound experimental design. Furthermore, the diet is not without risks. First, children who are on the diet have been found to have decreased bone density. For example, Hediger et al. (2008) examined cortical bone thickness (CBT) of male children diagnosed with an ASD. Results indicated that the CBT of boys with ASD increased as the children aged, but the rate of growth was slower over the years compared to typically developing children. The deviation of bone growth was two times greater for boys who were diagnosed with ASD and who were on the GFCF diet compared to boys diagnosed with ASD who were not on the GFCF diet (Hediger et al. 2008). Another negative implication of the diet is protein malnutrition. Arnold et al. (2003) conducted a study to look at nutritional deficiencies in children diagnosed with autism who were on a GFCF diet compared to children diagnosed with ASD who were not on a GFCF diet. The plasma levels of most amino acids were higher for children diagnosed with ASD and not on restricted diets when compared to children diagnosed with ASD and on GFCF diets. Thus, nutritional deficiencies were more evident in children with ASD on the GFCF diet.

At this time, the diet does not have sufficient empirical support to be implemented as a treatment for symptoms of ASD. Furthermore, children may be put at risk in regards to their health following the use of the diet. Therefore, at this time, the diet is only recommended for those who actually have an allergy to gluten or dairy products. With that being said, any children who are on a GFCF diet should be monitored medically.

Secretin

Secretin, a hormone that aids in digestion, has traditionally been used for diagnosing pancreatic disorders by administering a single injection intravenously and analyzing the pancreatic secretions (Metz et al. 2004). Secretin has been approved by the Food and Drug Administration (FDA) for this use only. Gastrointestinal (GI) problems are common in children with autistic disorder, with some estimates of up to half of children with autistic disorder exhibiting problems such as diarrhea, reflux, and/or food selectivity (Kuddo and Nelson 2003). Secretin was first investigated for its effect on symptoms of autistic disorder in 1998 by Horvath and colleagues. Horvath et al. (1998) described three children with autistic disorder who had undergone secretin injections in order to study pancreatic secretions secondary to GI complaints. Compared to the children in the study without autistic disorder, the children diagnosed with autistic disorder exhibited significantly more pancreatic secretions following the secretin injection. As anecdotal data, Horvath and colleagues also reported that at 5-week follow-up, parents of the children with autistic disorder reported decreased GI discomfort in addition to improved eye contact, alertness, and expressive language. Following publication of these findings, there was a dramatic demand for secretin injections by parents of children with autistic disorder resulting in a shortage of the hormone (Levy and Hyman 2005).

Researchers have sought to identify a possible mechanism of action for the reduction in autism symptoms following an injection of secretin. The most common theory has to do with a “brain-gut interaction” (Levy and Hyman 2005). That is, certain hormones produced in the gut are believed to act as neuropeptides, interacting with corresponding hormone receptors in the brain to influence behavior. Animal studies of secretin have demonstrated that secretin is capable of crossing the blood-brain barrier and that secretin receptors are present in the brain. Secretin has been found to have an activating effect on Purkinje cells, central cerebellar nuclei, the hippocampus, and the amygdala in rats (Koves et al. 2004; Kuntz et al. 2004; Welch et al. 2003). Increases in GABA levels have also been observed as a result of secretin injections (Kuntz et al. 2004; Yung et al. 2001). However, do differences exist in the amount of secretin or secretin receptors in the brains of children with autistic disorder compared to typically developing children? Nelson et al. (2001) found differences in the amount of vasoactive intestinal peptide (VIP), a hormone in the same family of neuropeptides as secretin, in children with autistic disorder. However, no differences in secretin receptors have been identified between children with and without autistic disorder (Martin et al. 2000). Therefore, any potential mechanism of action for secretin improving symptoms of autistic disorder remains unknown.

Following Horvath et al.'s (1998) findings, controlled studies of secretin and its effects on symptoms of autistic disorder rapidly began to appear. Among double-blind placebo controlled studies conducted from 1999–2004 ($n=15$), no studies found evidence supporting intravenous secretin (in either single or multiple doses and either porcine or human synthetic secretin) as an effective treatment for autistic symptoms (Levy and Hyman 2005). Dependent variables ranged from standardized measures of symptoms of autistic disorder, challenging behaviors, communication and social skills, GI symptoms, sleep, and weight. While some studies reported statistically significant differences on individual dependent variables (Coniglio et al. 2001; Corbett et al. 2001; Roberts et al. 2001; Sandler et al. 1999), overall, a clinically significant effect for secretin was not found. Ratliff-Schaub et al. (2005) investigated the use of a transdermal form of secretin (i.e., secretin cream) used daily over a 4-week period. They found no significant differences between secretin and placebo on behavioral measures of autistic symptoms.

Many studies involving secretin report symptom improvements for both treatment and control groups, suggesting a placebo effect (Carey et al. 2002; Roberts et al. 2001; Sandler et al. 1999; Sponheim et al. 2002). That is, parents reported improvements in symptoms regardless of whether the child received secretin or placebo. To test this effect, several of the researchers asked parents to report whether they believed their child received secretin or placebo (Chez et al. 2000; Coniglio et al. 2001; Coplan et al. 2003; Molloy et al 2002). In every study, parents were no better than chance at predicting their child's group membership. To further demonstrate, in one study 76 % of parents whose child received placebo indicated that they would continue the treatment, even after being informed that it had no effect (Sandler et al. 1999). Indeed, the prospect of a "cure" for autistic disorder symptoms in the form of a single injection is appealing to parents desperate for help. It is not uncommon for parents beginning any type of treatment to note improvements (Sandler and Bodfish 2000). Investments in the form of time and money as well as increased attention and reinforcement to positive, adaptive behaviors may be just a few of many factors that contribute to a placebo effect.

To add to the lack of support for the effectiveness of secretin in reducing symptoms of autistic disorder, some studies have actually found adverse effects on behavioral symptoms. Carey et al. (2002) found that children in both the secretin and placebo groups deteriorated on their scores on the Autism Behavior Checklist (ABC; Krug et al. 1993). Specifically, they found that children receiving secretin scored significantly worse on the hyperactivity subscale of the ABC. Similarly, Honomichl et al. (2002) collected data on sleep and found that nighttime awakenings were more frequent for children after receiving secretin. A combination of contradictory findings and little to no evidence of clinical efficacy has led many researchers to conclude that secretin is not an effective treatment for symptoms of autistic disorder.

Given the lack of support for secretin as a treatment for autistic disorder, why is it that many parents continue to consider it as a viable treatment option? Some clinicians continue to suggest that there may be a small subset of children with autistic disorder who respond positively to secretin injections. One study by Kern et al. (2002)

found a decreasing trend in challenging behaviors in a sample of five children who presented with GI upset (i.e., diarrhea). Following administration of secretin, diarrhea symptoms ceased and a subsequent decrease in challenging behaviors was observed. However, it is worth noting that it may have been the decrease in GI upset that led to increased comfort and mood and decreased irritability and challenging behaviors (Metz et al. 2004). Additional studies examining the plausibility of this subgroup effect (i.e., children with GI disturbances and autistic disorder benefit from secretin treatment) have been unable to replicate Kern et al.'s findings (Coniglio et al. 2001; Levy et al. 2003; Roberts et al. 2001).

The continued use of secretin in the treatment of autistic disorder presents several concerns. As with any pharmacological agent, secretin may result in adverse side effects and/or allergic reactions depending on the individual (National Institute of Child Health & Human Development 1998). In addition, while single-dose usage in adults is considered safe, the effects on children have not been studied long term. Furthermore, little is known regarding long-term effects of multiple dose use of secretin or the various forms of administration (i.e., intravenous, transdermal).

Supplements and Vitamins

These were first used to treat individuals diagnosed with schizophrenia, interventions utilizing vitamins began over 60 years ago (Rimland 1964). Since then, a variety of vitamins and supplements have been investigated for individuals diagnosed with an ASD to treat the core and/or associated symptoms of the disorders. In fact, about 30 % of parents of children diagnosed with ASD report using them (Green et al. 2006). These percentages rank supplement and vitamin use amongst the most utilized alternative treatments for ASD. Researchers have sought to identify a possible mechanism of action for the reduction in ASD symptomatology following the use of these vitamins or supplements. Some have reported that supplements and vitamins counteract biomedical errors that have occurred within the body. Reportedly, these errors can lead to the development of psychiatric disorders (Pfeiffer et al. 1995). A review of the most common vitamins/supplements utilized for individuals diagnosed with ASD is outlined below including vitamin B6 with magnesium and omega-3 fatty acid supplements.

Vitamin B6 with magnesium Improvements in ASD symptomatology, more specifically in speech and language, following the use of vitamin B6 was first reported over 3 decades ago (Bönisch 1968; as cited in Nye and Brice 2005). Numerous other studies have been conducted to investigate the potential benefits of this vitamin as a supplement; however most have utilized flawed research methodologies.

The first study conducted that utilized a sound experimental design (i.e., double-blind, placebo-controlled) to evaluate the effectiveness of this vitamin on ASD symptomatology was conducted in 1993. Tolbert et al. (1993) assessed symptoms of ASD grouped into the following domains: social, affective, sensory responses, language, and total scores from the Ritvo-Freeman Real Life Rating Scale for Autism (Freeman et al. 1986). The treatment group received 200 mg/70 kg of pyridoxine and 100 mg/70 kg of magnesium per day. No significant differences emerged from pre- to posttreatment for any of the subscales investigated. A significant reduction emerged on the total score; however, this was observed for both the control and treatment groups. Thus, results suggest that the administration of vitamin B6 and magnesium has no effect on the treatment of ASD symptomatology at these dosage levels. The authors noted that the dose utilized in their study was below than that from previous studies that reported positive findings and the reduced dosage was in an effort to reduce the risk of potential side effects.

Nye and Brice (2005) conducted a review of all randomized trials to examine the efficacy of administering vitamin B6 with magnesium. Their search for published articles prior to 2006 articles yielded only three studies that were double-blind, randomized, placebo controlled, and conducted on individuals diagnosed with an ASD (i.e., Findling et al. 1997; Kuriyama et al. 2002; Tolbert et al. 1993). Fifteen other studies were identified; however, they were eliminated from the review due to utilizing non-randomized designs. From the results of their review, Nye and Brice concluded that at this time research conducted yields insufficient support for the use of vitamin B6 with magnesium as a treatment for ASD.

Overall, relatively few adverse side effects have been reported following the use of B6 with magnesium; however, some researchers have reported neurotoxicity (i.e., peripheral neuropathy) following the use of B6 (Schaumburg et al. 1983). Not only do Schaumburg and colleagues report side effects, they further suggest that long-term use is unsafe and also strongly oppose the use due to the lack of studies demonstrating efficacy at this time.

Omega-3 fatty acids Omega-3 fatty acids are essential for normal growth and development. Researchers have reported associations between various neurodevelopmental disorders and fatty acid deficiencies (Richardson 2004). Reportedly and problematic, individuals diagnosed with an ASD have lower levels of these fatty acids (Meguid et al. 2008). At this time, the mechanism of action of omega-3 fatty acid supplements to ameliorate symptoms of ASD is unknown (Bent et al. 2009). Despite an unclear mechanism of action, it is a widely used alternative treatment for ASD. Green et al. (2006) reported that over 25 % of children diagnosed with an ASD are being treated with fatty acid supplements.

Many studies have been conducted in an effort to evaluate the effectiveness of omega-3 fatty acid supplements. Bent et al. (2009) conducted a systematic review of these studies. The inclusion criteria for their review consisted of studies conducted between 1966 and 2008 that utilized participants diagnosed with an ASD who were treated with omega-3 fatty acids, and included an outcome measure to evaluate the effectiveness of the supplement. Their review of six studies that met the inclusion criteria indicated that insufficient evidence exists to support this intervention for the treatment of ASD. Furthermore, five of the six studies reviewed lacked experimental control and only one study was conducted that utilized a sound experimental design (i.e., Amminger et al. 2007).

In their study, Amminger et al. (2007) conducted a randomized, double-blind, placebo-controlled study to investigate the effects of supplements for children that met diagnostic criteria for autistic disorder. Children in the treatment group received fish oil supplements and children randomly assigned to the placebo group received coconut oil. Assessments were conducted at baseline and at 6-week follow-up using the ABC (Aman et al. 1985). The ABC assesses symptoms across five subscales including irritability, social withdrawal, stereotypy, hyperactivity, and inappropriate speech. Results indicated that children in the treatment and placebo groups that participated throughout the entirety of the study did not score significantly different from each other at 6-week follow-up (Amminger et al. 2007).

Despite its popularity as a treatment for ASD, empirical evidence does not support the use of omega-3 fatty acids for the treatment of ASD. Fortunately, studies have also reported that no adverse side effects have been observed during trials of omega-3 fatty acids for those diagnosed with an ASD (Bent et al. 2011). However, fatty acids are safe only when they represent less than 10 % of dietary intake (Eritsland 2000). Thus, children receiving supplements should be guided by this recommendation or followed by a nutritionist.

Hyperbaric Oxygen Treatment (HBOT)

HBOT is FDA approved for the treatment of carbon monoxide poisoning, severe burn and wound healing, massive blood loss, and diving injuries such as decompression sickness (McDonough et al. 2003). HBOT involves inhaling a mixture of 20–100 % oxygen in a pressurized chamber, with atmospheric pressure (atm) typically above 2 (Leach et al. 1998). To begin treatment, the patient enters the chamber and pressure is gradually increased to the target atm. Oxygen is then delivered at the decided upon mixture of room oxygen and pure oxygen, usually for a period of

60 min. However, an individual session of HBOT varies greatly by pressure, oxygen ratio, duration, frequency, and number of sessions depending on the patient and the condition it is targeting (Leach et al. 1998). HBOT has been found to result in increased blood flow to the brain and has the ability to decrease inflammation and repair damaged tissues (McDonough et al. 2003). As a result, HBOT has been utilized in various other disorders as an alternate treatment including stroke, cerebral palsy, fetal alcohol syndrome, and traumatic brain injury. However, controlled research is lacking regarding the effectiveness of HBOT for these conditions.

Several conditions believed to be targeted by HBOT have been identified as possible mechanisms of action for children with autistic disorder, such as cerebral hypoperfusion, oxidative stress, and inflammation (Rossignol 2007). Cerebral hypoperfusion, or reduced blood flow to the brain, has been found in various anatomical locations in children with autistic disorder and appears to correlate with core behavioral symptoms (i.e., language, social, repetitive behaviors; Rossignol and Rossignol 2006). Proponents of HBOT argue that through increased oxygen flow to the brain, cerebral hypoperfusion may be reduced resulting in improvements in symptoms of autistic disorder. However, not all children with autistic disorder exhibit cerebral hypoperfusion and, even among those that do, the areas of the brain that are affected vary from child to child. Some researchers additionally argue that inflammation in the brain may contribute to hypoperfusion (Rossignol 2007). Given that HBOT has been shown to reduce inflammation in general, a reduction in cerebral inflammation may reduce cerebral hypoperfusion and lead to an amelioration of symptoms of autistic disorder.

Children with autistic disorder have been found to have increased oxidative stress, an inability for the body to properly detoxify reactive oxygen species at a sufficient rate (Rossignol 2007). Concerns regarding the effect of HBOT on oxidative stress, specifically whether it would raise it for children with autistic disorder, who already have increased levels, have been raised given that it produces reactive oxygen species. However, studies of HBOT have indicated that oxidative stress is either unaffected or even improved in some cases when pressures less than 2 atm are used for long term (Rossignol 2007). Therefore, HBOT may have the beneficial effect of reducing oxidative stress in children with autistic disorder. How this may affect the behavioral presentation of autistic symptoms, however, has not been studied.

The first preliminary study of HBOT for autistic disorder was conducted by Rossignol et al. (2007) with 18 children receiving 40 sessions of HBOT. Rossignol et al. investigated the safety of HBOT for children with autistic disorder as well as measured the effect of HBOT on oxidative stress, inflammation, and behavioral symptoms of autistic disorder. Rossignol et al. found that at doses of 1.3 and 1.5 atm, only one child was unable to tolerate the pressure, concluding that HBOT appears safe at low doses. Measures of oxidative stress and inflammation yielded minimal improvements for some of the children and no change for others. Finally, parent-report measures of behavioral symptoms of autistic disorder indicated improvements in irritability, social withdrawal, hyperactivity, motivation, speech, and sensory/cognitive awareness. However, the open-label nature of the study and lack of a control group makes it difficult to draw conclusions regarding the efficacy of HBOT for autistic symptoms.

To follow-up the preliminary study, Rossignol et al. (2009) conducted a double-blind placebo controlled study of HBOT for children with autistic disorder. In order to maintain the blind nature of the study, a dose of 1.1 atm was used for the control group so that pressurization in the chamber could mimic that of the treatment group, which received 1.3 atm. Again, 40 sessions of HBOT were administered. Rossignol et al. reported that significant group differences were found. That is, autistic symptoms as measured by standardized parent report measures significantly decreased for children in the HBOT treatment group. They concluded that HBOT was an effective treatment for autistic symptoms. However, Granpeesheh et al. (2010) argue that the authors' conclusions were not supported given the statistical analyses used. Granpeesheh et al. note that differences between the treatment and control group were not significantly different in the Rossignol et al.'s study. That is, both groups reported improvements in ASD. Where statistical differences between groups were found, they were minimal and unlikely to produce significant clinical differences (Granpeesheh et al. 2010).

Granpeesheh et al. (2010) performed their own double-blind placebo controlled trial consisting of 80 sessions of HBOT at 1.3 atm for the treatment group. A greater number of outcome measures were used than had been in previous studies, including both clinician and parent report standardized measures. Granpeesheh et al. reported improvements in both groups, but no significant differences between groups on any of the dependent measures. They concluded that HBOT is not effective for treating symptoms of autistic disorder, even when delivered twice the previously studied 40 session treatment length.

HBOT has not been shown to be a clinically effective treatment for symptoms of autistic disorder in controlled studies conducted to date. While the side effects of HBOT are rare, they include middle ear barotauma, sinus squeeze, serous otitis, claustrophobia, reversible myopia, and new onset of seizures (Rossignol and Rossignol 2006). In addition, studies have found that patients may drop out due to claustrophobia and/or anxiety related to being in the chamber for an extended period of time (Granpeesheh et al. 2010; Rossignol et al. 2009). The price of HBOT can cost more than US$ 15,000 for one person, with variations depending on the length of the treatment (McDonough et al. 2003). This can be quite a financial undertaking, particularly for a treatment with little empirical support.

Chelation Therapy

Chelation involves the administration of binding agents, typically dimercaptosuccinic acid (DMSA), to bind to heavy metals in the body and facilitate excretion through urine (Akins et al. 2010). Chelation with DMSA is FDA approved for use in adults and children with heavy metal poisoning. Some proponents of chelation therapy argue that by removing heavy metals from the body, recovery of neurocognitive functioning can occur. However, researchers have been unable to demonstrate this effect in controlled studies. In fact, findings suggest no improvements in neurodevelopmental symptoms following chelation (Dietrich et al. 2004; Rogan et al. 2001).

Use of chelation for autism became relevant following a publication by Bernard et al. (2001) comparing symptoms of mercury poisoning to symptoms of autistic disorder. Bernard et al. argued that given similarities between the symptoms of mercury poisoning and autistic disorder, it was plausible that autism was a form of mercury poisoning. They cited symptom onset following vaccinations, a correlation between prevalence of autistic disorder and increases in vaccines, a higher ratio of males to females in both conditions, the heritability of autism and a genetic predisposition to mercury sensitivity, and parent reports of high levels of mercury in children with autistic disorder as evidence for the proposed autistic disorder-mercury relationship. Bernard et al. (2002) specifically targeted thimerosal, a mercury-based additive included in many childhood vaccinations up until 2002.

In 2003, Nelson and Bauman published a review examining the claims made by Bernard et al. (2001). Nelson and Bauman (2003) note that Bernard et al. list several overlapping symptoms between autistic disorder and mercury poisoning; however, they fail to indicate which are the most characteristic versus rare symptoms of each. For example, common motor impairments observed in children with mercury poisoning include ataxia and dysarthria, rarely seen in children with autistic disorder. As such, Nelson and Bauman conclude that there are several distinct core features that differentiate mercury poisoning from autistic disorder.

Regarding a temporal relationship between vaccinations and onset of symptoms, Nelson and Bauman (2003) note several weaknesses in Bernard et al.'s (2001) argument. First, temporal association does not establish causation. Second, retrospective parental report of symptom onset is often poor and may result in erroneously relating the beginning of the disorder to another recognizable event (e.g., vaccinations). Finally, numerous studies on vaccines and autistic disorder have been conducted and have found no evidence of a relationship (Chen and DeStefano 1998; Dales et al. 2001; Peltola et al. 1998; Taylor et al. 1999). In fact, prevalence studies have found continued increases in autistic disorder diagnoses despite decreases and/or plateaus in vaccination rates and elimination of thimerosal from vaccines (Dales et al. 2001). As such, the official stance of the American Academy of Pediatrics (Halsey and Hyman 2001), Institute of Medicine (Stratton et al. 2001) and the Immunization Safety Review Committee (Williams et al. 2008), is that there is no causal relationship between vaccines and autistic disorder.

Nelson and Bauman (2003) also investigated Bernard et al.'s (2001) argument that children with autistic disorder have higher levels of mercury in their systems. However, research has been unable to confirm this hypothesis. Studies of mercury in hair samples of children with autistic disorder and typically developing children have failed to find significant differences between the two groups (Ip et al. 2004; Wecker et al. 1985; Williams et al. 2008). The difficulty in confirming an excess of mercury in children with autistic disorder leads to additional concerns regarding the safety of chelation in children. A study by Stangle et al. (2007) found that when DMSA was administered to rats without excessive lead in their system, long-term cognitive and emotional problems resulted. As such, the use of chelation without evidence of heavy metal exposure in children may have negative consequences.

The continued use of chelation therapy as a treatment for autistic disorder is alarming given the lack of empirical support for the rationale underlying its use and efficacy. Chelation therapy can result in serious side effects including neutropenia, kidney dysfunction, liver damage, paresthesias, Stevens-Johnson syndrome, and in some cases, cardiac arrest due to hypocalcemia (Akins et al. 2010). In 2006, the CDC reported three deaths (i.e., two children and one adult) following chelation therapy secondary to hypocalcemia. One of the children was being treated for autistic disorder. Based on concerns regarding risk versus benefit, the National Institute of Mental Health (NIMH) canceled plans for the first controlled trial of DMSA in children with autistic disorder (Mitka 2008). Given the lack of evidence for a link between excess mercury and autistic disorder, the use of chelation therapy for these children should not only be considered ineffective, but potentially harmful.

Animal Therapy

Animal therapy is used in the treatment of a variety of disorders for adults and children. Animal therapy for autistic disorder may include the use of dogs as service animals, horse riding, and dolphin-assisted therapy, just to name a few. Advocates for animal therapy argue several benefits including improvements in social skills, decreases in maladaptive behaviors, and increased motor skills (Grandin et al. 2010). However, research regarding the efficacy of animal therapy consists largely of case studies and anecdotal reports. In addition, theories regarding the mechanism of action for animal therapy vary based on the specific therapy and symptoms of the child, and is highly speculative in nature with little empirical support.

The use of a service animal, such as a dog, for children with autistic disorder is commonly for safety purposes (Burrows et al. 2008). That is, a dog may alert parents when their child gets out of bed during the night or prevent the child from running away when outside. However, behavioral improvements have also been reported from the use of a service animal including elevated mood, increased attention, and improved social and communication skills (Martin and Farnum 2002). Explanations for these observed improvements vary from simple reinforcement and positive experiences with the service animal to sensory-based connections between the child with autistic disorder and the animal (Grandin et al. 2010). That is, children with autistic disorder have a difficult time understanding and interpreting verbal and nonverbal aspects of human communication. However, animal communication occurs solely through nonverbal behavior which may be more easily understood by children with autistic disorder. Perhaps a more parsimonious explanation for perceived improvements in autistic disorder symptoms may be through the inherent increased social opportunities (e.g., others coming up to the child to meet the service animal, family members playing together with the service animal, increased family outings due to an extra "safety net" with the service animal) that coincide with having a service animal (McNulty 2009, as cited in Grandin et al. 2010).

Horses may be used with children with autistic disorder in a variety of ways (Grandin et al. 2010). Recreational riding is a less structured activity often used as reinforcement for other treatment/training techniques. Therapeutic horseback riding targets physical and motor improvements through riding such as posture, balance, and mobility, and is conducted by a certified riding instructor. Hippotherapy incorporates components of therapeutic riding with a more comprehensive treatment plan that uses riding as reinforcement for other training techniques and is conducted by an occupational or physical therapist (Gabriels et al. 2012). All forms of therapy with horses report a social aspect between both trainer and child and horse and child. While there are obvious physical benefits to riding (e.g., balance, posture, muscle tone), possible mechanisms of action for improvements in attention, social, and communication symptoms include enjoyment of the activity, increased social and language exposure with trainers in the presence of a reinforcer (i.e., the horse), and reinforcing vestibular sensory stimulation secondary to rhythmic movements of the horse (Grandin et al. 2010).

There have been few controlled studies examining the effectiveness of therapeutic riding and hippotherapy for children with autistic disorder. Bass et al. (2009) compared children receiving therapeutic riding to a wait-listed control group and found significant improvements on parent report measures of social motivation, sensory integration, and attention. Bass and colleagues acknowledge the potential bias given the non-blind nature of the study and use of parent report alone. More recently, Gabriels et al. (2012) conducted a pilot study of therapeutic riding for children with autistic disorder using both objective and parent report outcome measures. Compared to a wait-list control group, children participating in therapeutic riding exhibited significant improvements in self-regulation, motor control, and communication. Gabriels et al. hypothesized that the sensory experience of riding may induce a sense of calm, resulting in decreased irritability, stereotypic behaviors, and hyperactivity. In addition, communication skills may be fostered through interactions with trainers and horses (e.g., instructing the horse to "walk on"). Gabriels et al. call for more well-controlled studies of hippotherapy to address possible confounding variables such as the increased interaction and attention provided by the trainers, the highly reinforcing nature of the activity, sensory stimulation, and report bias due to the non-blind nature of existing studies.

Dolphin assisted therapy (DAT) involves swimming and interaction with dolphins in captivity or in the wild. In many cases, traditional training takes place and interaction with the dolphin is used as reinforcement for completion of work tasks (Williamson 2008). The extent of interaction with the dolphins varies and may include fin rides, swimming in the tank with the dolphin, or more educational activities regarding training on the care of the dolphin. Proponents of DAT argue that it has several benefits including increasing attention span, motivation, and language and that these results are seen more quickly with DAT than in other traditional forms of therapy (Nathanson 1998; Nathanson et al. 1997). However, as with most animal therapies, research on DAT is scarce, particularly for children with autistic disorder. Of the research that is available, there are many methodological flaws including lack of control groups and procedural integrity that would allow conclusions regarding efficacy to be drawn (Marino and Lilienfeld 2007). At best, research on DAT suggests that observed improvements following treatment are more likely the result of placebo or novelty effects. Marino and Lilienfeld (2007) argue that DAT is a reinforcing experience for some children that likely produces a "temporary feel good effect" (p. 248). However, given the risks involved with interactions with a wild animal (i.e., risk of injury or infection), the use of DAT as a treatment technique should be considered unethical and irresponsible.

Based on the available research, animal therapy shows some promise in improving symptoms of autistic disorder. However, due to a lack of empirical research, it is unclear whether these therapies act as true treatments on their own or simply provide positive experiences that reinforce skills learned from more traditional therapy techniques. In addition, little is known regarding the maintenance of treatment outcomes once therapy has ended. Parents and consumers should be cautious when exploring these alternative treatments and thoroughly weigh the risks and benefits. If anything, reported benefits from animal therapy provide support that pairing reinforcing experiences with consistent training may lead to symptom improvements for children with autistic disorder.

Facilitated Communication

Facilitated Communication (FC) is an augmentative communication technique that was developed in the late 1970s in Australia and rapidly spread in late 1980s and early 1990s to the USA and other westernized countries, primarily Canada and western Europe. Initially created by Rosemary Crossley to increase the communication of individuals with cerebral palsy (Crossley and McDonald 1980; Crossley 1992), the use of FC has also generalized to people with autism spectrum disorders and other developmental disabilities in the USA (Biklen 1990, 1992, 2005; Biklen et al. 1992; Biklen et al. 1995). The use of FC and its widespread acceptance as a treatment choice for children with ASD has mainly occurred through information being disseminated, supported by, and promoted via training and workshops in other nations and an established network of FC service providers. Likewise, the establishment of the Facilitated Communication Institute at Syracuse University by Biklen in 1993 has further assisted with the expansion of FC to the mainstream audience (Biklen 2005).

FC has been described as a strategy that individuals with limited communication skills can successfully communicate and convey their thoughts by typing or pointing at letters on an alphabet board or by using a typing device (Biklen 1990, 1992, 2005). The premise of FC was based on the belief that with additional support, the user would be able to demonstrate his/her true capacities thereby increasing independency and overall quality of life. In FC, the individual is seated at a keyboard or other letter-displaying instrument. A trained facilitator supports the communicator to communicate by holding and/or physically guiding the individual's hand, arm, and, elbow, or pointer finger to select or point to letters on the keyboard or visual display. According to FC's proponents, the function of the facilitator is to assist the muscular control of the communicator by holding the communicator's arm steady, and yet be noninfluential so that the communicator will "get his or her own words out" and communicate in a way "that had been previously thought impossible" (Biklen 1992; Crossley 1994). The goal of the facilitator is to fade their level of support over time, allowing the individual to communicate without assistance.

FC has been deemed a controversial treatment due to inconsistencies determining the authorship of the individual's message. Out of all of those who cast the first cloud of suspicion on FC, the investigation by Wheeler et al. (1993) is often cited as the classic case whereby researchers were able to demonstrate that some facilitators unknowingly influenced the message of the person they were assisting. In their experiment, researchers selected 12 individuals who were proficient producers of FC. Each pair (communicator and facilitator) was shown a series of pictures of objects (e.g., hat, bread, car, etc.) and were then asked to label the object. The communicator and his/her facilitator were seated side by side, but were separated by a partition so that each person could not see the picture presented to the other. Three different experimental conditions were arranged. In the first, the communicator was presented with a picture, no picture was presented to the facilitator, and the communicator was asked to identify the picture through the use of FC. In the second condition, the communicator was presented with a picture, no picture was presented to the facilitator, and the communicator was asked to identify the picture without the use of FC. Although the facilitator could not provide physical assistance in the second condition, he/she could use verbal prompts to assist the communicator. In the third condition, both the communicator and facilitator were presented with a card; however in half of the trials the cards were identical and in the other half they were different. Results of multiple presentations of these manipulations by Wheeler and colleagues found that the communicators did not produce accurate labels or descriptions of pictures unless facilitators were shown the same pictures. Furthermore, the communicators were also observed to type out labels or descriptions of the pictures in situations where the pictures were shown only to the facilitators.

Since the investigation by Wheeler and colleagues, a base of literature has amassed on the inconsistencies and inadequacies of FC (ref Bebko et al. 1996; Bomba et al. 1996; Braman and Brady 1995; Cabay 1994; Crews et al 1995; Eberlin et al. 1993; Klewe 1993; Montee et al. 1995; Moore et al. 1993; Myles et al. 1996; Regal et al. 1994; Shane and Kearns 1994; Simpson and Myles 1995; Smith et al. 1994; Szempruch and Jacaobson 1993; Wheeler et al. 1993). These studies have differed substantially in many respects including the kind of tasks involved, the characteristics of the clients and facilitators, the setting of the experiment, and the type of experimental design. Across all of the well-controlled investigations to date, researchers have consistently documented the role of facilitator influence and/or that the message attributed to nonspeaking autistic or developmentally delayed subjects are the exclusive product of facilitator cuing (Mostert 2001; Jacobson et al. 2005). Similarly, the few reports of validated communication under controlled circumstances have been described as occurring erratically amidst extensive cued typing, and as linguistically rudimentary, far below the level of sophistication attributed to subjects.

The research since the mid-1990s dealt a significant blow to the FC movement. Due to the lack of FCs scientific validity, a number of national organizations including the American Psychological Association (APA 2003), along with the American Academy of Pediatrics (AAP 1998), the American Speech-Language-Hearing Association (ASHA 1995), and other scientific and professional organizations have issued official resolutions indicating their failure to support FC. Many of these organizations e.g., Association for Behavior Analysis International have gone so far as to warn professionals of the risks of the technique as well as deem the continued use of FC as unethical (ABAI 1995).

Despite the overwhelming data to disconfirm the use of FC, the strategy still has its proponents and continues to be used in various capacities. In 2008, the parent-based nonprofit organization Autism National Committee (or AutCom) affirmed their belief that FC is “one accepted and valid way in which individuals with autism can exercise their right to say what they have to say” (AutCom 2008). It is reasonable to see how parents would buy into FC. The rationale behind this strategy would be appealing to parents and caregivers because it enables them to believe that their nonverbal child may one day become able to communicate their wants and needs. Families may be told for the first time that by using FC their child will be able to share their thoughts and feelings and therefore, parents may begin to believe that FC will work for their child. This is not to say that the proponents of FC do not acknowledge the controversial nature of the strategy. The Association for Persons with Severe Handicaps (TASH) does state that the topic of authorship with respect to FC has “become particularly controversial when the subject of what has been communicated concerns sensitive issues” (TASH 2000). Advocacy groups claim that the criticism of FC is based upon studies which are “poorly designed and/or whose results are incorrectly extrapolated to the entire population of FC users” (AutCom 2008). Proponents of FC also assert that FC is valid for some persons, and as such it should be continued for those where real user-author communication does occur. Furthermore, TASH advocates that as the FC movement is continued that that “rigorous and ongoing training” is undertaken for facilitators so that they are able to able to “careful, reflective use” of FC (TASH 2000). As recently as 2009, a bill was introduced to the Massachusetts legislature requesting that teachers be mandated to receive training in FC to use as a treatment for students with disabilities (S. 223 2009). Despite the preponderance of research suggesting otherwise, it appears that due to the unfortunate number of consumers and providers believing that FC is effective this fad will continue to persist.

Sensory Integration Therapy

Sensory Integration Therapy (SIT) is based on theoretical assumptions first developed by Ayres (1972, 1979). This treatment is a form of sensory-motor therapy which has been applied to not only children with autism, but also those with learning disabilities, behavioral problems, intellectual disability, cerebral palsy, and other developmental disabilities (Watling et al. 1999; Case-Smith and Miller 1999; National Board for Certification in Occupational Therapy 2004; Spitzer et al. 1996). Sensory integration is a normal developmental process which involves the ability of the central nervous system to organize sensations from the environment and from within one’s body. Ayres posited that children with autism or similar developmental disabilities have deficits in registering and modulating sensory input, and a deficit in the part of the brain that initiates purposeful behavior, which is termed the “I want to do it” system (Schaaf and Miller 2005). SIT, typically delivered in an individual session format, attempts to ameliorate the supposed underlying neurological processing deficits through sensory integration. SIT is most commonly used within occupational therapy programs, although some of the techniques may be used by teachers or other professionals. In a survey of occupational therapists, 82 % of respondents reported that they “always” use a sensory integrative approach when working with children with ASD (Watling et al. 1999).

In an attempt to facilitate the integration of sensory information, SIT involves engaging the individual in full body movements designed to provide input in the vestibular, tactile, and proprioceptive systems. The vestibular system, located in the inner ear, integrates sensory input from the vestibular organs, eyes, and muscles, and allows a person to maintain balance and understand where they are in space. The tactile system coordinates sensory input through the sense of touch and disintegration of the tactile system is sometimes evidenced as tactile defensiveness. The proprioceptive system integrates sensory input received through muscles and joints, and is the primary mechanism for motor control and posture. It is believed that sensory difficulties, particularly those in autism, are due to a dysfunction in one or all three of these systems (Ayres 1972, 1979). Stock-Kranowitz (1998, p. 292) states that for children with autism their problem with sensory integration hinders them due to an “inefficient neurological processing of information received through the senses, causing problems with learning, development, and behavior.” The purpose of sensory integration, then, is to come to an understanding of how these different types of sensory input have an impact on the child’s behavior and learning, and then attempt to change how the brain processes and organizes sensations by providing sensory stimulation allowing the child to effectively begin learning (Bundy 2002).

This method of modifying the child’s ability to learn via additional sensory input is often referred to as designing a “sensory diet” for the child. A sensory diet may incorporate environmental modifications, such as reducing unnecessary distractions, changing lighting, modifying classroom tools and materials, and adding specific sensory stimulation techniques. Sensory activities which may be incorporated into SIT include swinging in a hammock, applying brushes to various parts of the body, deep pressure, playing with textured materials, wearing a weighted vest, using a vibrating massager, carrying heavy objects, and engaging in balance activities (Bundy 2002; Schaaf and Miller 2005). According to supporters of the intervention, these sensory experiences are hypothesized to correct the underlying neurological deficits producing the perceptual-motor problems occurring in those with autism or similar developmental disabilities (Hodgetts and Hodgetts 2007).

A growing literature base has amassed that addresses the outcomes and efficacy of the sensory integration approach. Daems (1994) reviewed the outcomes of 57 studies published between 1972 and 1992 that evaluated interventions based on SIT. More recent reviews (Leong and Carter 2008; Miller 2003; Parham et al. 2007) and meta-analyses (Vargas and Camilli 1999) have indicated that there may be at least 80 published articles that address sensory integration outcomes. Across all of these reviews, it has been demonstrated that for those studies which were well-designed rigorous studies (e.g., included objective measures of behavior, a control group or a second treatment comparison, baseline measures, etc.) results overwhelmingly fail to show that treatments based upon sensory-integration theory are effective in reducing symptoms or ASD and/or providing any clinically-relevant benefit to individuals receiving the intervention.

In a comprehensive review by Leong and Carter (2008) of research on the efficacy of SIT from 1997 to 2007, findings demonstrated a lack of solid evidence to support the use of SIT. The authors went so far as to conclude that the continued use of SIT, given the lack of evidence for its effectiveness, is not justified and may even be contraindicated. For example, Mason and Iwata (1990) compared the effects of SIT and a behavioral intervention within a multiple-baseline across subjects design. During the application of SIT in their study, Mason and Iwata observed that self-injury increased above baseline levels in a 3-year-old participant; however, problem behaviors were later reduced when behavioral interventions were prescribed. Findings similar to that of Mason and Iwata (1990) have also been found by Devlin et al. (2009, 2010) for children with ASD and self-injury. That is, severe problem behaviors did not significantly decrease when SIT was applied and in some cases increased; however, when function-based behavioral interventions were utilized clinically-significant reductions in problem behaviors were observed. These three investigations (Devlin et al. 2009, 2010; Mason and Iwata 1990) raise concerns about the active components of SIT and also call into question the continued and widespread use of SIT for decreasing problem behaviors in children with ASD and other developmental delays.

SIT remains a popular treatment among various consumers despite lack of evidence for its efficacy (National Board for Certification in Occupational Therapy 2004; Schaaf and Miller 2005; Watling et al. 1999). SIT is a resource intensive intervention that is often incorporated with other treatments for autism resulting in an “eclectic” approach. Because of the nature of SIT, it is often proposed as a necessary treatment option for stereotypy or behaviors maintained by automatic/sensory reinforcement. Green (1996) pointed out that although children may find SIT activities enjoyable, this does not provide evidence of any significant, long-lasting benefits in the child’s behavior or in any underlying neurological deficits. Furthermore, although applying certain sensory activities (e.g., brushes of increasing firmness to the arms of autistic children) may help to desensitize them to certain stimuli, such benefits are most parsimoniously explained by well-known behavioral principles (e.g., habituation) rather than anything specific to SIT (Smith et al. 2005). Proponents of SIT do acknowledge that there may be some limitations to their approach. However, the vast majority of advocates of this approach indicate that the “supposed drawbacks” are the result of the limited research available which is due to a “lack of funding, paucity of doctorate trained clinicians and researchers in occupational therapy, and the inherent heterogeneity of the population of children affected by sensory integrative dysfunction” (Schaaf and Miller 2005). However, at this time, based on the literature to date, it appears that the actual limitation to SIT is not funding, but rather is the lack of proven effectiveness.

Auditory Integration Training

Auditory integration training (AIT) was developed by Berard (1993, 2006), an ear, nose, and throat doctor. Proponents of AIT claim that the beneficiaries of this treatment suffer from an inability to organize and process auditory information. Furthermore, this dysfunction not only inhibits the individual's ability to hear but also impairs their ability to learn, comprehend information, and remain focused in/on their environment. How AIT became applied to those with ASD is based upon literature which posits that those with autism show a higher incidence of sensory processing difficulties than the general population (e.g., Baranek et al. 1997; Gillberg et. al. 1990). As a result, practitioners have proposed that AIT is a therapeutic approach aimed at reducing or eliminating auditory sensory processing challenges in those with ASD. The belief is that when individuals with ASD organize their auditory processing abilities, they will become more receptive to other therapies (AIT Institute 2010).

Although there are many variations within AIT (e.g., Berard Method, Somanoas Method, Tomatis Method), the general methodology consists of the recipient listening to music or sounds that have been digitally modified in some way. The actual AIT therapy is applied in an intensive format which involves the individual listening to music/sounds for a total of 10 h, subdivided into 20–30-min sessions across the span of 10 days. The music/sounds are altered in various ways such as dampening or limiting the peak frequencies, randomly varying the high and low frequencies on a random basis, or varying the volume. The auditory sound is modified in particular ways based upon the supposed needs and challenges of the recipient (Berard 2006). The premise is that upon listening to the random variations in sounds the individual's auditory system adjusts to the sounds and thus becomes more normal. The goal of AIT, then, is to "retrain" the acoustical reflex muscle (AIT Institute 2010). In theory, once hearing is retrained persons with ASD will become less sensitive to particular sounds in their environment, and a reduction in sound distortion will be evident. Proponents of AIT claim that benefits include improvement in memory, comprehension, eye contact, articulation, independent living skills, appropriate social behavior, willingness to interact with others, and responsibility in school (Berard 1993; Rimland and Edelson 1994).

Although the advocates of AIT claim that there is scientific evidence to support this therapeutic approach (Edelson et al. 1999; Rimland and Edelson 1994, 1995), the methodological and statistical procedures employed in these studies have been reported to be highly controversial and flawed. As a result, literature supporting the use of AIT has not been widely accepted by the scientific community (Dawson and Watling 2000; Goldstein 2000; Mudford and Cullen 2005; Sinha et al. 2006). Sinha et al. (2006) conducted a recent review of the AIT methods, limiting their review only to those investigations were researchers employed randomized control trials with individuals diagnosed with ASD. Out of the six studies identified, outcomes indicated that AIT was either ineffective to control conditions, or that the reported behavior changes were due to repeated measures on behavior rating scales, not AIT. Sinha and colleagues concluded that there was, at the time, no evidence sufficiently powerful or reliable to support the belief that AIT was empirically proven to be effective. This inability of researchers conducting well-control studies to find supportive evidence for the continued use of AIT has also resulted in public stances against the continued use of this technique by organizations such as the AAP (1998) and the ASHA (2004). ASHA (2004) went so far as to adopt a policy statement indicating that there was no evidence that AIT improves the behavior of persons who use this treatment, and any ASHA member could be found in violation if he/she choose to employ AIT.

Despite the lack of conclusive evidence for AIT with respect to effectiveness in persons with ASD, the use of this therapy continues. It is true that compared to other fads, AIT does offer several perceived advantages including the parent being permitted to remain with their child during the treatment sessions, a clear time commitment, and the use of "fancy" technical equipment. In an internet survey of parents of children with ASD, Green et al. (2006) found that almost half of respondents indicated using a physiological-based treatment with AIT being ranked as the 3rd most used treatment in this category. Given that the proliferation of AIT as well as other fad treatments may continue to persist, Mudford and Cullen (2005) suggest that parents who are considering purchasing AIT to improve their children's behaviors should reconsider in light of the lack of valid evidence supporting AIT. Romanczyk et al. (2003) also cite reports of negative side effects which they argue raise ethical questions concerning the use of this procedure with people with autism. AIT is one of the more expensive treatment options for people with autism. Furthermore as Romanczyk and colleagues point out, AIT uses equipment capable of producing sounds at decibels that may be harmful to a person's auditory system, and therefore it is important that the intervention only occur under the direction of a trained AIT specialist. However, we would posit that regardless of whether AIT is carried out by a trained specialist or not, the time and money families would waste on this ineffective treatment as opposed to investing it in other empirically-supported treatments renders AIT a useless and, potentially harmful treatment option.

Conclusion

ASDs are a set of neurodevelopmental conditions typified by impairments in social interaction and communication, as well as excesses in restricted interests and/or repetitive behaviors. Symptoms of autism are reported to emerge early in life and persist throughout the individual's lifetime. Although there have been recent advancements in treating and understanding the etiological aspects of ASD, autism-related disabilities continue to remain largely enigmatic. The heterogenous nature of ASD across those diagnosed with the condition further compound the ability to pinpoint effective interventions. The purpose of this chapter was to provide a thorough review of the more popularized controversial and unsupported therapies often used with children diagnosed of having ASD. It is our belief that by reviewing the information contained herein parents and professionals will be able to cast a critical eye on the "latest and greatest" treatment touted by an enthusiastic celebrity, professional, or parent advocate. By being familiar with the literature one is better able to make informed decisions which will be beneficial and in the best interest of the client and his/her family. It is highly plausible that parents may continue certain therapies (e.g., dolphin or equestrian therapy, SIT) not because it provides any significant learning experience or increases the child's ability to function more independently, but because their child genuinely enjoys participating in activity.

We would advocate that, regardless of the child's preferences, evidence-based practices are the central component to any treatment package. In short, evidence-based treatments are those which have amassed a base of research conducted by multiple investigators (other than the main, or central, treatment advocate) that use operationally defined terms, give significant subject/participant details, have reliable measures of behavior change, utilize rigorous experimental designs, and control for multiple sources of bias and other threats to internal validity (Kasari 2002; Newson and Hoanitz 2005; Reichow et al. 2008).

At this time, treatments which have the most empirical support in the literature with respect to effectiveness are those based upon applied behavior analysis (Newson and Hoanitz 2005; Tuzikow and Holburn 2011). Treatments for young children with ASD which can be classified as being based on behavioral principles (i.e., operant learning theory), may vary in their immediate focus; however, they share common features which include: (a) an individualized curriculum focusing on deficit areas (e.g., selective attention, imitation, language, communication, toy play, and social skills); (b) highly supportive teaching environments with explicit attention to the generalization of treatment gains; (c) an emphasis on predictability and routine; (d) a function-based approach to manage challenging behavior; (e) a focus on appropriate educational placements; and (f) parental or caregiver involvement in treatment (Matson and Minshawi 2006; Sturmey and Fitzer 2007). Although treatments grounded in behaviorism have the most support with respect to well-controlled research, it should be stated that, at this time, there is no known "cure" for ASDs. Persons with ASD are not a homogenous group—meaning that not everyone symptomatically presents exactly the same. For even those treatment modalities with empirical support, the complex nature of the diagnosis of autism has significant implications with respect to prognosis, treatment planning, and treatment outcomes.

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Families of Children with Autism Spectrum Disorders: Intervention and Family Supports

24

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Keywords

Parent involvement · Family supports · Siblings

Autism spectrum disorders (ASD) are characterized by communication and social impairments, and restricted and repetitive behaviors and interests (American Psychiatric Association 2000; Diagnostic and Statistical Manual of Mental Disorders). Children with autism also often engage in challenging behaviors such as tantrumming, elopement (e.g., leaving a designated area without adult supervision), aggression, and self-injury (Baghdadli et al. 2003; Conroy et al. 2005; Horner et al. 2002). These core deficits represent a significant disability affecting child development, but also present unique and persistent challenges to the child's parents and other family members.

Without intervention, the core deficits of ASD tend to persist over time and can negatively affect a child's educational and social outcomes (National Research Council 2001). Moreover, child-specific characteristics such as delayed communication (Moes 1995), social skills deficits (Baker-Ericzén et al. 2005), challenging behaviors (Baker et al. 2002), and diagnostic severity (Tobing and Glenwick 2002) have been associated with increased parent stress. Challenging behaviors especially are predictive of worsened parent outcomes (Bernhiemer et al. 1990; Lecavalier et al. 2006; Lucyshyn et al. 2004; Seltzer et al. 2001a), impaired sibling relationships (Greenberg et al. 1999; Orsmond et al 2009), and later adjustment difficulties (Hastings 2007). Early intensive behavioral intervention (EIBI) may be effective in reducing the impact of the disorder on child and family functioning (Harris and Handleman 2000; Howlin et al. 2009; Lovaas 1987, 1993, 1996; McEachin et al. 1993;

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Smith et al. 2000a; Weiss 1999) and may indirectly decrease parent stress through improved adaptive behaviors (Smith et al. 2000b). However, the pervasiveness of ASD often necessitates intensive and prolonged intervention that requires effortful identification and coordination of a family's resources and a parent's consistent involvement in their child's education (e.g., Sallows and Graupner 2005).

Parenting a young child can at times be incredibly positive, stressful, and overwhelming (Crnic and Greenberg 1990). Certainly parents of children with autism experience the typical highs and lows, joys and struggles facing all parents and a growing body of longitudinal research suggests that the negative effects of raising a child with a developmental disability may not be as commonplace or serious as previously thought (Seltzer et al. 2001b; Glidden and Jobe 2006; Singer 2006). Nevertheless, parents of children with developmental disabilities such as ASD often experience heightened levels of stress (Hastings and Beck 2004; Keenan et al. 2010; Koegel et al. 1992; Schieve et al. 2007). Mothers and fathers of children with ASD have reported more stress than parents of children with other developmental disabilities, children with special health care needs, and children without special needs (Keenan et al. 2010; Schieve et al. 2007). Although some researchers have found similar levels of stress for both mothers and fathers of children with autism (Hastings 2003; Noh et al. 1989), mothers especially may be affected by caregiving responsibilities, experiencing more stress, anxiety, and depression than fathers (Meadan et al. 2010; Moes et al. 1992). Typically developing siblings may also be affected by having a sibling with autism in unpredictable ways, both positive and negative (Stoneman 2005). Although the majority of past research has focused on mothers of children with ASD, we know comparatively little about the potential positive and negative outcomes for siblings who have a brother or sister with an ASD (Stoneman 2005; Yirmiya et al. 2001).

As with all families, the quality of the sibling relationship varies across families of children with ASD (Orsmond and Seltzer 2007; Sage and Jegatheesan 2010). However, sibling relationships in families of children with an ASD may differ in important ways from the relationships of typically developing siblings, or siblings of brothers or sisters with another developmental disability, such as Down syndrome (Fisman et al. 1996; Wolf et al. 1998). Siblings of children with disabilities and special health care needs often take on caregiving and educational roles (Benderix and Sivberg 2007), may receive less parent attention (McKeever 1983), and may participate infrequently in community activities (Dyson 1989). Siblings of children with ASD may also experience feelings of neglect and overwhelming responsibility (e.g., McHale et al. 1986), and may encounter challenging behavior such as aggression during attempted interactions with their brother or sister (e.g., Ross and Cuskelly 2006). These factors influence the sibling-family relationship over time (Lobato et al. 1988). This influence, however, is not always negative and typically developing siblings may be well adjusted (Taunt and Hastings 2002), experience less sibling rivalry than usual, and benefit from a more cohesive family (Kaminsky and Dewey 2001). Additionally, a sibling's prosocial overtures toward their brother or sister with an ASD provide models of age-appropriate social skills (Knott et al. 2007) and their involvement in intervention (e.g., Strain and Danko 1995) may directly contribute to positive outcomes for their sibling with ASD and indirectly improve their family's overall quality of life.

A number of recent reviews have summarized studies evaluating the aforementioned issues relevant to parent and sibling implemented intervention and family supports (e.g., Brookman-Frazee et al. 2006; Friend et al. 2009; Kim and Horn 2010; Lang et al. 2009; Matson et al. 2009; McConachie and Diggle 2007; Peters-Scheffer et al., in press; Schultz et al. 2011; Singer et al. 2007; Warren et al. 2011). Behavioral skills training for parents has effectively addressed child-specific behavior, such as functional communication (e.g., Koegel et al. 1996), and decreasing challenging behavior while teaching skills that have been demonstrated to result in decreased parent stress (e.g., Feldman and Werner 2002; Koegel et al. 1996; Schreibman et al. 1991) and depression (e.g., Bristol et al. 1988). Similarly, siblings have implemented evidence-based interventions with their sibling with autism (e.g., Reagon et al. 2006; Strain and Danko 1995; Swenson-Pierce et al. 1987; Tsao and Odom 2006), and have also benefitted from participating in support groups such as Sibshops (Meyer and Vadasy 1994). Additionally, families often use informal and formal family support services (e.g., respite, parent to parent support groups; Chan and Sigafoos 2001; Santelli et al. 2002) and have benefitted from interventions directly targeting parent stress (Hastings and Beck 2004). However, we are unaware of any review that summarizes extant literature for all of these essential issues.

The purpose of this chapter is to review peer-reviewed studies evaluating (a) parent involvement in EIBI; (b) interventions to improve parent skills in an effort to improve a range of child behaviors (e.g., communication and social skills, challenging behavior); (c) typically developing siblings as interventionists; (d) family support practices; and (e) interventions to decrease parent stress. The main purpose of such a review is to summarize extant literature for practitioners and researchers, to identify gaps in the literature, and to provide recommendations for future research and practice. The remainder of this chapter is organized into findings, and concluding remarks and future research. In the findings section, within each topical area, we provide an overview of the issue, summarize the research, and discuss trends and issues in the literature. The concluding remarks and future research section provides an overall discussion of findings and provides suggestions for future research.

Findings

Parent Involvement in Early Intensive Behavioral Intervention

A growing number of alternative therapies claim positive outcomes for children with ASD (Schreibman 2005; Schreck and Miller 2010; Smith and Antolovich 2000), but applied behavior analytic interventions have the most empirical evidence of effectiveness for treating ASD and at this time are the only evidence-based interventions (National Research Council 2001; Schreibman 2000; Sherer and Schreibman 2005). Therefore, best practices for treatment following diagnosis include EIBI, or comprehensive applied behavior analytic intervention delivered to children 5 years old and younger (see Peters-Scheffer et al. 2011 for a review of comprehensive EIBI programs). Unlike focused interventions, which are implemented for a limited period of time to improve specific targeted behaviors (Hall 2009; Machalicek et al. 2007, 2008), comprehensive applied behavior analysis (ABA) models of intervention center around intensive intervention (typically 20–40 h each week for 2 or more years). Intervention consists of carefully structured, massed teaching trials or discrete trial training (DTT; Leaf and McEachin 1999; Lovaas 1981) and/or naturalistic ABA intervention approaches including incidental teaching (e.g., Hart and Risley 1975), pivotal response training (PRT; e.g., Koegel et al. 1987, 1989); and enhanced milieu teaching (e.g., Kaiser et al. 2000; Kaiser and Hester 1994). Communication and social skills, play, self-help and independent living skills, challenging behavior, cognition and preacademic skills are often targeted with consideration of typical child development (Leaf and McEachin 1999; Vismara and Rogers 2010). Additionally, some EIBI programs first teach foundational or readiness skills such as joint attention, compliance, attending/orienting to stimuli, choice making, and imitation (e.g., Frea and McNerney 2008). Currently, EIBI models that are procedurally well described, have been replicated, and have some evidence of efficacy include or are associated with: (a) the Denver Model, (b) Learning Experiences: An Alternative Program for Preschoolers and Parents (LEAP), (c) the Lovass Insititute, (d) May Institute, and (e) the Princeton Child Development Institute (see Odom et al. 2010 for a review of comprehensive EIBI models). Across each of these models, well-prepared clinicians supervise program development and delivery and rely on significant parent involvement. Although researchers continue to debate the number of required hours and methodology of intervention, and the targeted skills and curriculum, there is general consensus that intensity of the program contributes significantly to positive child development, (Eldevik et al. 2006) as does parent participation (Sallows and Graupner 2005). Empirical evaluations of the effectiveness of EIBI programs have included both clinic-based (Ben-Itzchak and Zachor 2007; Eikeseth et al. 2000; Fenske et al. 1985; Harris et al. 1991) and home-based programs (Anderson et al. 1987; Birnbrauer and Leach 1993; Eikeseth et al. 2002; Howard et al. 2005; Lovaas 1987; McEachin et al. 1993; Sheinkopf and Siegel 1998). Although center-based programs encourage and often require some level of parent participation, for logistical reasons, parents are generally more actively involved in home-based programs.

There are a number of benefits of involving parents in EIBI. As the primary caregivers, parents can improve the quantity and quality of intervention, their involvement can improve the generalization of positive educational outcomes to home and community settings, and their participation may decrease stress and improve coping strategies. Moreover, active collaboration with parents in assessment and the selection of goals and objectives, intervention procedures, and outcomes aligns with family-centered practices in early intervention (Dunst et al. 1994) and may improve the contextual fit of interventions and contribute to improved treatment adherence (Hieneman and Dunlap 2001). This section reviews intervention studies involving parents as part of an EIBI program.

Summary of the Research

Parents have been involved in many aspects of EIBI programs including identifying intervention goals, managing their child's program(e.g., hiring and training therapists), and participating in parent education programs aimed at teaching basic ABA principles and their application to their child's daily routines. The outcomes of parent-directed EIBI programs for children with ASD and their parents have varied with mixed results reported in the literature. The research can be grouped into child outcomes following parent-directed EIBI and parent outcomes following parent-directed EIBI.

Child Outcomes

Parent-directed EIBI programs may result in outcomes similar to clinic-based EIBI programs (Sallows and Graupner 2005). Sallows and Graupner's experimental group design study compared the outcomes of a clinic-directed program and a parent-directed program for 24 children with autism, who were assigned to the two groups through a matched random process. Children in the clinic-based group received an average of 38 h of intervention a week and the parent-directed group received 31.5 h of intervention a week (one child received 14 h a week) with less frequent professional supervision. Somewhat surprisingly, children in both groups showed similar, positive improvements in adaptive behaviors, language, social skills, academics, and IQ. Sallows and Graupner suggested that the positive results might be explained by parents' motivation and willingness to ensure high quality intervention (e.g., filling cancelled therapist shifts themselves, arranging play dates, taking on the senior therapist role).

However, a larger number of researchers have reported less than optimal progress when parents, rather than experienced behavior analysts manage the child's EIBI program (Bibby et al. 2002; Smith et al. 2000b; Smith et al. 2000c). Bibby et al. (2002) evaluated the effects of parent-initiated approximations to the UCLA workshop model (Lovaas 1996) that included significant parent participation on the developmental outcomes of 66 children with ASD using an accelerated multi-cohort longitudinal design (Kazdin 1998). Participating children began EIBI at a mean age of 45 months, and at the time of the first assessments in this study, the majority of the children were in their second year of intervention. Children received a mean of 30.3 h of therapy each week with parents managing aspects of their child's therapy, but the extent to which paid therapists and parents directed and/or implemented intervention was unknown. Standardized assessments, parent interview, and direct observations of the child in their family home were conducted twice, approximately 12 months apart. Adaptive behavior gains were identified in 33 % of children and 27 % experienced significant IQ gains. However, among the findings of this study was that none of the 42 children that were at least 72 months of age and had received 2 or more years of intervention had outcomes meeting Lovaas's (1987) criteria for "best outcome." Bibby et al. (2002) suggested that pretreatment variations in participating children, or the quantity and quality of received intervention might have contributed to these outcomes. There is growing evidence to support an explanation of differential responding to intervention due to individual child characteristics (Ben-Itzchak and Zachor 2007; Howlin et al. 2009; Sherer and Schreibman 2005). Additionally, variation in EIBI program implementation (e.g., quality and frequency of supervision) is common (Love et al. 2009).

Parent Outcomes

Although parents have long been involved in or directed their child's EIBI program, we know little about the impact of participating in EIBI programs on family functioning (Grindle et al. 2009; Howlin et al. 2009). The findings of recent studies examining the effects of mothers' participation in EIBI suggest that many parents will desire some level of participation in EIBI, find EIBI beneficial (Boyd and Corley 2001; Dillenburger et al. 2004; Grindle et al. 2009), and are unlikely to suffer serious negative consequences from participating (Birnbrauer and Leach 1993; Hastings and Johnson 2001; Smith et al. 2000b). These findings do not discount the stress of daily experiences that families participating in EIBI encounter, such as the potential loss of privacy due to therapists regularly entering their home; and difficulties obtaining funding, managing therapists, and administering the program (e.g., Cattell-Gordon and Cattell-Gordon 1998; Grindle et al. 2009). However, for many families, the stress of participating in EIBI may not be more than the day-to-day stress they experience as a parent of a child with an ASD. For instance, Hastings and Johnson (2001) found that mothers participating in EIBI reported similar amounts of stress to mothers of children with autism who were participating in other research studies.

Trends and Issues

Parent involvement in EIBI is naturally aligned with early intervention philosophies and family-centered practices. Additionally, mothers and fathers may indirectly benefit from their child's improved behaviors (e.g., communication, play, and social skills) and directly benefit from increased knowledge about ABA, and increased social support and respite (Grindle et al. 2009). Moreover, parents may not experience higher levels of stress when participating in their child's EIBI program. However, there are several issues that should be further examined.

Research evaluating parent and clinic-managed EIBI programs suggests that parent-managed EIBI, while resulting in positive child outcomes in adaptive behaviors, IQ, and language (Bibby et al. 2002; Smith et al. 2000b; Smith et al. 2000c), may not result in outcomes as promising as those obtained in clinic-managed EIBI programs (e.g., Harris and Handleman 2000; Harris et al. 1991; Lovaas 1987). These differential results may be partly explained by the fewer weekly hours of intervention received by children in parent-managed programs (Smith et al. 2000b). Smith et al. (2000b) reported that children, on average, received a mean of 30.3 h each week; that is almost 10 fewer hours of one-to-one intervention each week when compared to Lovaas (1987). Future research evaluating parent-managed and/or implemented programs should evaluate methods to increase the quantity and quality of one-to-one intervention in the child's home. Additionally, clinic-based EIBI programs might improve family outcomes by systematically including and evaluating beneficial aspects of parent-directed programs, such as parent education, family choice of targeted objectives and therapists, and family supports such as respite care.

Practitioners and researchers have long suggested that one way to increase the amount and quality of intervention received by a child with autism is to prepare the parents to deliver the intervention (Schopler and Reichler 1971). However, the creation and management of an effective, long-term EIBI program requires sufficient time, resources, and the involvement of trained, experienced professionals such as board certified behavior analysts (BCBA). When parents are in charge of managing their child's EIBI program and have received insufficient support from professionals or are unable to regularly achieve weekly therapy hours, their child's outcomes may be less positive than expected. Parents will likely benefit from increased access to consultancy to maintain necessary levels of treatment fidelity to ensure child progress and technical assistance to identify, hire, train, and supervise in-home therapists. The quality of an EIBI program is largely based upon the quality of the delivered intervention and practitioners should anticipate that many parents will approach EIBI lacking some or all of the skills needed to adequately manage their child's program.

In summary, parents can and often do play an essential role in the management and delivery of EIBI, but family members participating in EIBI will benefit from ongoing support from behavior analysts and other professionals (e.g., speech and language therapists, physical therapists, special educators, and mental health specialists) on their child's treatment team, as well as parent education and supports focused on skill acquisition and stress reduction.

Behavioral Skills Training

Parents often have an active role in guiding the education and social-emotional development of their children (e.g., Hart and Risley 1995; Kaminski et al. 2008). Research has demonstrated that parents of children with autism can be taught to accurately deliver interventions designed to improve their children's communication (e.g., Vismara and Rogers 2008), social skills (e.g., Mahoney and Perales 2003), and challenging behavior (e.g., Moes and Frea 2002). Parent-implemented interventions have ranged in complexity from simple single-component interventions (e.g., differential reinforcement) to complex multi-component intervention packages (e.g., DTT; Lafasakis and Sturmey 2007). A considerable amount of research has focused on identifying procedures that can be used to teach parents to accurately implement behavioral interventions to their children with autism. This section presents a selective review of studies involving behavioral skills training for parents of children with ASD.

Summary of the Research

Across the body of research involving parent-implemented interventions, a variety of different training procedures have been used (Lang et al. 2009; Matson et al. 2009; Meadan et al. 2009). The two most common training procedures are verbal and written instructions (Lang et al. 2009). Verbal instructions involves providing parents: (a) an explanation of the intervention's mechanism of action (i.e., why the intervention is likely to be effective), (b) a detailed description of specific intervention procedures, and (c) question-and-answer-based discussions. For example, R. L. Koegel et al. (2002) and Symon (2005) used trained therapists to deliver verbal instructions to parents on how to implement PRT. While verbal instructions were provided, parents and therapist observed the children together, discussed the goals of the intervention, built rapport, and reviewed the intervention procedures.

Written instructions are often provided to supplement verbal instructions (Schultz et al. 2011). Written instructions can range from simple one-page formats used during intervention to prompt specific intervention procedures to more extensive published treatment manuals that provide details on intervention components and implementation (Schultz et al. 2011). Stiebel (1999) provided parents with a manual that included a template designed to guide parents through a decision-making process involving the Picture Exchange Communication System (PECS). Specifically, the template was designed to help parents identify communication breakdowns and use PECS to address those breakdowns. The parents then used the written instructions to successfully implement PECS to three children with autism, 4–6 years of age, in their homes.

Role-play is a parent training strategy that involves the parent implementing the intervention with the trainer (or other person) pretending to be the child. Role-play allows the parent to practice the intervention procedures without the complexity of the child with autism being involved. For example, R. L. Koegel et al. (2002) taught four fathers, five mothers, and one grandmother to implement PRT with five children with autism (each child had two participating parents) using a multi-component parent training approach that included role-play. The parents took turns pretending to be the child and implementing PRT while receiving feedback and coaching from the trainers. The children's expressive verbal communication improved as a result of the intervention and the parents' ability to implement PRT was maintained at 3 and 12 months.

Modeling is a parent training procedure that involves the trainer demonstrating how the intervention should be implemented. Hames and Rollings (2009) implemented a group-based parent training program that involved video-modeling designed to improve parents' ability to interact with their children who had intellectual and developmental disabilities and engaged in challenging behavior. A questionnaire sent to the parents that attended the group training sessions over an 8-year period identified that 64 % of the parents believed the training had led to improvements in their children's challenging behavior.

Another common parent training approach is performance feedback from the trainer. Performance feedback involves the trainer observing the parent implementing intervention and then providing reinforcement for correctly implemented procedures or verbal instructions contingent upon errors in implementation. Feedback can be provided in real time or during review of video recordings of the parent implementing intervention (Lang et al. 2009). For example, Vismara and Rogers (2008) videotaped a parent implementing the Early Start Denver Model (ESDM) intervention to a 9-month-old infant suspected of having autism. As part of a multicomponent parent training approach, the researchers watched the video with the parent and provided feedback. Results of this case study demonstrated that the parent was able to accurately implement ESDM and, ultimately, reduce the child's severity of autism symptoms.

The majority of studies that involve teaching parents to implement complex multicomponent interventions (e.g., DTT and PRT) have involved a combination of the above teaching procedures, and it is not uncommon for a study to utilize all of the above approaches (Lang et al. 2009). For example, Kaiser et al. (2000) taught parents to implement EMT using verbal instructions, role play, and review of videotaped sessions with feedback. This combination of parent training procedures resulted in parents learning to implement the environmental arrangement strategies, responsive interaction, and prompting and reinforcement inherent to EMT. Additionally, parents generalized skills from the university-based clinic (training setting) to their homes.

Trends and Issues

Although the above parent training procedures are often effective, the range of symptom presentation in ASD, level of parent education and experience, and other pragmatic issues (e.g., time parents have available to implement intervention) would seem highly likely to influence the success of parent training and parent-implemented intervention (Matson et al. 2009). Therefore, additional research focused on the factors that influence the successful training of parents and the effects of parent-implemented intervention is warranted. For example, Lang et al. (2009) reviewed research in which parents were trained to implement communication interventions to children with autism. Studies were excluded from the review if the parents' ability to implement specific intervention components was not measured in baseline. This ensured that improvement in parent ability was measured in at least a pre/post test or AB design. The result of focusing only on studies with baselines of parent behavior was that only 11 studies involving only 60 parents qualified for inclusion in the review. Of that group, none of the studies involved a component analysis to determine the contribution of individual training procedures, and an absence of parent demographic information was noted across studies. Similar issues regarding research designs and the absence of parent participant characteristic information have been reported in other literature reviews covering parent-implemented social, communication, and challenging behavior interventions (Matson et al. 2009; McConachie and Diggle 2007; Meadon et al. 2009; Schultz et al. 2011). Therefore, definite statements regarding the most efficient and effective approaches to training parents to implement interventions to autism are not yet possible and additional research in this area remains warranted.

Sibling-Mediated Intervention

Historically siblings have often been informally included as part of the home-based intervention process for children with ASD (Ferraioli et al., in press). There are many benefits for both the target child and other family members as a result of this inclusion, including improved family functioning and stronger bonds between the sibling and target child. The sibling is also likely to develop a greater understanding of the target child's condition and needs (Reagon et al. 2006) and may be motivated to learn to play appropriately with him or her. Furthermore, siblings are considered to be ideal models because of their daily proximity to the child with ASD and their perceived status. There is also an opportunity for the transferability of skills between home and school (Celiberti and Harris 1993).

However, the formal inclusion of siblings as natural change agents did appear in the literature until the 1970s. These early studies focused on specific skills including dropping chips in holes (Cash and Evans 1975) and bead stringing (Colletti and Harris 1977). During the 1980s the skills being taught by siblings became somewhat more functional and included self-help (Lobato and Tlaker 1985) and domestic skills (Swenson-Pierce et al. 1987). Schreibeman et al. (1983) took the procedure of including siblings in the intervention process to a new level of functioning by teaching them how to implement a series of behavior modification skills, including shaping and reinforcement (Tsao and Odom 2006). These early studies indicated that siblings could be an important and successful part of the therapeutic process. This section presents a selective review of studies evaluating sibling-mediated interventions for children with ASD.

Summary of the Research

When siblings are unable or unwilling to play with each other in a productive and positive way additional stress may be put on parents. Thus, if one of the key aims of therapy for a child with autism is to improve family functioning, it is somewhat surprising that it was not until the 1990s that researchers in the ASD field began to focus on improving the relationship between siblings. Strain and Danko (1995) were among the first to study sibling-implemented interventions using a withdrawal of treatment design to teach parents to encourage positive interactions between young children with autism and their siblings. They implemented a school-based social skills intervention package that had been adapted for caregivers. It included video clips of sibling pairs playing together appropriately by displaying five different interactional strategies. The findings demonstrated that all three families were able to effectively implement the package, which resulted in marked improvements in the percentage of positive interactions between siblings.

As noted by Tsao and Odom (2006), despite the publication of a few exemplary articles the specific use of siblings as change agents to improve social behavior in children with ASD is still a relatively under-researched field. Celiberti and Harris (1993) published the first study in this area and highlighted the importance of learning to play appropriately with their siblings in the overall social development of children with ASD. This skill was considered to be age appropriate and likely to result in an improved sibling relationship. They utilized a multiple-baseline design across three activities with three sibling pairs. The siblings were taught to elicit play related speech, praise play behaviors, and prompt when the target child failed to respond. Clear differences were found between baseline and intervention for all sibling pairs on all three activities. In addition, the generalization and follow-up data revealed that the newly acquired skills were also displayed with different toys and in different settings for up to 16 weeks after the completion of the study.

Taylor et al. (1999) conducted two play based, multiple baseline probe design studies with two sibling pairs. Each child viewed their respective sibling producing positive play related statements with an adult while engaged in three different play activities. In the first experiment the target child viewed the video three times and then practiced the scripted play statements with an adult. During probe sessions, which were conducted before the intervention/practice sessions the sibling pairs were instructed to play together. The sibling made scripted statements. Results revealed that the target child had learned to make the scripted comments during all three activities. In the second experiment the authors used a forward chaining method that focused on the number of unscripted comments made by the target child. The child viewed the video, which depicted his sibling playing with an adult and was then able to play with materials represented in the video. A nearby adult praised him for any relevant comments he made about the play materials. Probe sessions were conducted with the sibling after the target child had completed the forward chaining procedure and met acquisition criteria. The results showed a meaningful increase in the target child's unscripted comments about the play materials as compared to baseline.

Reagon et al. (2006) also implemented a video-modeling intervention. The aim of the study was to teach pretend play skills to a 4-year-old child with autism, using his sibling as both a video model and a play partner. The authors sought to replicate and extend the Taylor et al. (1999) study by simplifying procedures and conducting the study in a center rather than in the child's home. Four play scenarios were implemented in an AB design. During intervention the pair watched a video clip and were then instructed to "*Go play*" with no additional instructions or prompts. The results revealed that the number of scripted play actions and scripted statements increased during intervention and were maintained during a follow-up session in the child's home. The number of spontaneous words did not appear to be influenced by the intervention, however, the authors note that there was an increase in complexity from single words to longer statements. Again, as noted by the authors this study was limited by the research design and inclusion of only one participant.

A recent focus in this area has been joint attention. As Tsao and Odom note in the introduction to their 2006 article, it is an early emerging skill, which is critical to the overall development of social behavior in children with ASD. One of the aims of their study therefore was to see if they could see an improvement in the amount of joint attention exhibited by the children with ASD. Their study involved a multiple-baseline design across four sibling dyads. The siblings participated in 10-min social skills lessons targeting a range of social interaction skills. The results revealed modest positive changes in the social behavior of the target children and moderate changes in the behavior of the nondisabled siblings. There were also significant increases in the amount of joint attention exhibited by the target children; however, the skills taught did not appear to generalize to an alternative setting.

Ferraioli and Harris (2011) included four sibling dyads in a multiple baseline across participants design. Siblings were trained to teach joint attention skills to their sibling with ASD using a procedure developed by Whalen and Schreibman (2003), which involves eight sets of goals and accompanying procedures. The results indicated that all four participants demonstrated gains in responding to joint attention and three participants demonstrated gains in initiation.

Trends and Issues

There are a number of important issues arising from the sibling as change agents literature that are worthy of consideration. In their review of sibling-mediated interventions, Ferraioli et al. (2011) highlight the importance of a sibling's motivation to be a social agent. Interventions take time and patience and therefore a sibling needs to have as much age-appropriate information as possible in order for them to understand the purpose and procedures of the intervention as well as the learning difficulties that the target child may have. This process is considered to be a vital component in order to ensure high levels of motivation on the part of the sibling. Furthermore the power differential between the sibling and the target child needs to be managed. Finally, materials and activities need to be interesting and engaging, particularly when working with young children, and the siblings need to be reinforced for their involvement.

The second issue involves the assumption generated by these articles that siblings are perhaps better models than peers or adults. Jones and Schwartz (2004) have disputed this assumption. They compared the relative effects of sibling, adult, and peer models on a picture stimuli task for children with ASD in a parallel treatments, single case research design study that was counterbalanced across sets and replicated across participants. They found that although child models were more effective than adult models, siblings were not necessarily any more effective than peers in improving outcomes.

In conclusion, this sample of studies involving siblings as change agents demonstrates the potential for positive outcomes. Thus, sibling-mediated interventions appear to have the potential of becoming an important component of the intervention process. Currently, however, the paucity of studies precludes definitive conclusions, and additional research in this area remains warranted (Ferraioli et al. 2011; Tsao and Odom 2006).

Family Support

Many parents report increased levels of stress after their child receives an ASD diagnosis (Ornstein-Davis and Carter 2008). Coupled with the ongoing demands placed on family resources, family support services are often deemed necessary to ensure optimal outcomes for the child with ASD and his or her family. Depending on the region of the world in which the family lives, different support services are available. For example, in the USA, families with children or adults with intellectual and developmental disabilities are supported via federally funded services that vary across states. These services may include family counseling, respite care, financial assistance, assistive technology and environmental modification, adaptive medical equipment, personal assistance, transportation, recreation, and provision of specialized clothing and foods tailored to specific dietary needs (Rizzolo et al. 2009).

While it may be obvious that family and child outcomes are greatly enhanced through the delivery of effective support services such as respite care programs (Chan and Sigafoos 2000), other factors are not as apparent. Specifically, questions that must be answered include: (a) what services to provide, (b) how to provide such services, and (c) when to provide services to families. Unfortunately, few researchers have empirically examined specific family supports and limited research is available to guide the provision of family support services (Friend et al. 2009). Nevertheless, this section provides an overview of the available research in this area in an attempt to identify current best practices in the delivery of family support services and concludes with a brief discussion of the components of family support.

Summary of the Research

One of the most prevalent forms of support for families of children with ASD is participation in a support group or one-to-one peer support. Home-visiting or center-based early intervention programs often provide such supports as part of a family-centered model of practice (e.g., Hendriks et al. 2000; Mahoney and Bella 1998). Support groups, led by peer parents (Law et al. 2001) or co-facilitated by experts from different fields (Banach et al. 2010), have been shown to increase empowerment and self-efficacy of parents who participate in the groups. One-to-one peer mentoring programs (Ireys et al. 1996; Rosenberg et al. 2002) and parent to parent models of support (Ainbinder et al. 1998; Singer et al. 1999) for children with developmental disabilities or special health care needs have demonstrated positive outcomes including increased family acceptance of the child's disability (Singer et al. 1999) and decreased mental health symptoms (Ireys et al. 1996). Additionally, families rated peer support as helpful (Rosenberg et al. 2002; Singer et al. 1999) and were more likely than other parents of children with special needs to progress in obtaining assistance for disability-related issues (Ireys et al. 1996; Rosenberg et al. 2002; Singer et al. 1999). However, parent contact with a parent to parent organization did not result in changed perceptions of empowerment (Singer et al. 1999). These supports offer various levels of assistance: (a) emotional support by creating a sense of belonging through discussion of common experiences, successes and challenges; (b) an opportunity to share their experiences with their child's behavior with other parents who have similar concerns; (c) access to valuable resources; and (d) informational support through presentations regarding such issues as diagnosis, assessment and intervention, special education laws, and advocacy. Similarly, families may benefit from assistance identifying their informal social support network using such assessment tools as Eco-mapping (McCormick et al. 2008). Ekas et al. (2010) found that support in the form of a partner, family, and friends was correlated with increased optimism. This increased optimism was found to contribute to improved positive outcomes for mothers, suggesting a need to focus on the creation, strengthening, and maintenance of naturally occurring social support groups for parents of children with ASD.

Banach et al. (2010) evaluated the effects of a co-facilitated support group on the advocacy and self-efficacy skills of parents with children who recently received a diagnosis of an ASD. A special educator and a social worker led this particular group. The support groups, consisting of either five or nine parents, were implemented using a psycho-educational approach; in addition, families were provided with resource packets and childcare during the group. Some of the topics that were covered over the course of the six sessions included: advocacy skills, challenging behavior, and the individualized education plan (IEP) process. An interesting component of one session was having a panel of experienced parents come in to discuss their own experiences. After participating in the support group, parents reported a greater degree of empowerment, competence and confidence in approaching service systems.

Another form of support that is often available to families of children with ASD is respite care. The goal of respite care is to provide temporary caregiving assistance to parents of children with disabilities and/or provide a break from parenting responsibilities for a short period of time. Respite care has been associated with reduced parent stress (Chan and Sigafoos 2001; Cowen and Reed 2002) and depression (Herman and Marcenko 1997). Upon examining child and family characteristics that influence the utilization of respite services Chan and Sigafoos (2000) found that the following child characteristics were predictive of the use of respite services: (a) severe disabilities, (b) high levels of personal care needs, (c) challenging behaviors, (d) communication difficulties, and (e) at least 11 years of age. In many communities there are often extensive waiting lists to access these services, which likely accounts for the majority of children receiving respite services being 11 years or older.

Trends and Issues

Researchers have considered parental perceptions of support services and consistently find that there are areas that parents would like more information. For example, in an attempt to understand how a child with an ASD influences family dynamics, Cassidy et al. (2008) explored parental perceptions of child difficulties, impact of the child on family life, supports available to families, and supports families would like to be able to access. Results indicated that 79 % of the parents felt that there could be improvement in services offered to them. The top two areas in which parents desired additional information were coping with their child's behaviors and background information about the causes and symptoms of ASD. These findings parallel the findings of Banach et al. (2010) who reported that participants suggested including more information of the school education process.

Additionally, some families may benefit from two-generation programs that simultaneously focus on child intervention and family supports based upon an individualized family support plan to address parent's educational, self-sufficiency, mental health, and health and nutrition goals (See Friend et al. 2009, for a review). These programs have been used by Head Start Family Service Centers (St. Pierre et al. 1996) and Early Head Start (Love et al. 2002) to improve child and family functioning.

In summary, families of children with ASD may achieve improved outcomes through accessing and utilizing family support services such as respite care or support groups. The majority of the literature evaluating these supports focuses on the method of service delivery rather than considering which services (i.e., respite, support group, type of support group) may be more beneficial to families or when different services are most needed by families. Additionally, the majority of existing research focuses on support groups and there is a need for research investigating the impact of other types of support on child and family outcomes.

Interventions to Decrease Parent Stress

Parents of children with ASD report higher levels of stress compared to parents of typically developing children. High levels of parental stress may have a negative impact on the effectiveness of intervention programs for children with ASD (e.g., Osborne et al. 2008). Osborne and Reed (2010) have shown that parental stress was related to self-perceived parenting behaviors in 138 young children with ASD. Specifically, high levels of parenting stress resulted in lower self-perceived involvement, communication, and limit setting toward their child.

Child challenging behaviors are strongly associated with increased levels of parental stress (e.g., Hastings et al. 2005; Herring et al. 2006). For example, Peters-Scheffer et al. (2012) explored predictors (child variables) of maternal stress in 104 mothers of children with ASD and severe to mild intellectual disability. Regression analyses revealed no significant predictors (e.g. IQ, severity and symptoms of ASD, joint attention skills) of maternal stress, except for children's emotional and behavioral problems, which explained a third of the variance in maternal stress.

Parental stress is related to access to autism-related services. For example, Thomas et al. (2007) investigated parental stress and service use in a community sample of 383 families with a child with ASD, aged 11 years or younger. Results showed that when parents reported higher levels of stress they used a greater number of services such as child-oriented services (e.g., medication, communication programs) and family-oriented services (e.g., respite care).

Parental stress may have several adverse consequences and attention for interventions aimed at decreasing stress in parents of children with ASD is therefore needed. This section presents a selective review of studies involving interventions aimed at reducing elevated levels of stress in parents of children with ASD.

Summary of the Research

Although relatively few studies have been published in this area, three groups of published studies aimed at decreasing parental stress may be distinguished: (a) interventions directed at reducing children's challenging behaviors, (b) interventions directed at educating parents, and (c) interventions directed at improving parental psychological functioning.

Interventions for Children's Challenging Behavior

Assuming that the relationship between parental stress and children's challenging behaviors is causal, one may predict that treatment programs targeting children's challenging behaviors lead to reduced parental stress. McConachie and Diggle (2007) conducted a systematic review of parent-implemented interventions for children with ASD between the ages of 1 and 6 years. Few studies could be located and results showed that parent training not only lead to improved functioning of the child but also to reduced maternal depression. For instance, Smith et al. (2000b) assessed parental stress levels in 6 mothers who followed a parent-directed program. Results showed that their stress level had substantially decreased following the program. Results of a study by Smith et al. (2000c) strongly suggest an association between the intensity of the parent program and parental stress. That is, parents who had followed an intensive program reported less stress than parents who had followed a less intensive parent-training group. These studies indicate that parents of children with ASD receiving intensive behavioral intervention report less stress during and following such programs.

Sofronoff and Farbotko (2002) evaluated the effectiveness of an intervention for parents of children with Asperger syndrome who showed challenging behavior. Intervention was aimed at increasing parental self-efficacy and management techniques for dealing with their child's challenging behavior. One group of parents received a 1-day workshop and the other group of parents received several individual sessions. Results showed that following intervention parents of both experimental groups showed more self-efficacy and reported less challenging behavior in their child than parents in the control group. Interestingly, mothers showed a larger increase in self-efficacy than fathers. No significant differences were found between the two experimental groups.

Parent education programs A small number of studies have assessed effectiveness of parent education programs and factors that may enhance their effectiveness. In a recent study, Steiner (2011) investigated effects of a 'strength-based' approach as opposed to a 'deficit-based' approach on the level of parent affect, their statements regarding the behavior of their child with autism, and the quality of parent–child interactions. During the strength-based approach the therapist made statements that highlighted the child's strengths or potential. Statements were made in the context of developing or altering intervention procedures to capitalize on these areas of strength. This approach was compared to a deficit-based condition in which the therapist made statements regarding the child's weaknesses. Results showed that parent affect was more positive in the strength-based condition compared to the deficit-based condition. Also, parents displayed more positive affect toward their child in the strength-based condition during parent–child interactions. Although the effectiveness of either procedure on parental stress was not assessed, the results suggest that a strength-based parent education program may improve parent affect as well as parent–child interactions, which may reduce the stress level experienced by parents.

Acceptance and Commitment Therapy Though it is acknowledged that parents of children with autism face enormous challenges, little attention has been paid to their psychological needs. Acceptance and Commitment Therapy (ACT) may be effective in improving psychological functioning in parents of children with ASD. Blackledge and Hayes (2006) assessed the effectiveness of a 2-day group ACT workshop on 20 parents/guardians of children diagnosed with autism. Parents were assessed 3 weeks before, 1 week before, 1 week after, and 3 months after the workshop. No significant change occurred while waiting for treatment, but pre to posttreatment improvements were found on measures of depression and general psychological functioning.

Trends and Issues

Although there are overlapping features, type of stressors and intensity of stress posed on parents are unique. The systemic analysis of an intervention for parental stress should be individually tailored to the unique constellation of family characteristics. As an example of the latter, differences in stress and coping styles between mothers and fathers should be taken into account. For example, Lee (2009) found that on average mothers adapted a more active coping style than fathers in dealing with the practical challenges of raising their child with high-functioning ASD. Also, sources of stress may be different for mothers than for fathers of children with autism (e.g., Hastings 2003).

Interventions to reduce parental stress should be directed at promoting an active problem solving coping strategy as opposed to avoidance coping (see Hastings and Beck 2004). Interventions should also be directed at: reframing or positive perceptions by parents (see e.g., Hastings and Taunt 2002), parental self-efficacy (see e.g., Kuhn and Carter 2006), and acquiring social and professional support (e.g., seeking communications with other parents e.g. via internet, Sarkadi and Bremberg 2005; Luther et al. 2005; Lee 2009; Twoy et al. 2007).

Concluding Remarks and Future Research

Families of children with an ASD face unique difficulties related to the provision of EIBI, the need to learn the principles of ABA and specialized skills in instruction, increased stress levels, and increased support needs for themselves and other family members. In this chapter, we reviewed the intervention and family support literature targeting parents and siblings of children with ASD. Specifically, we focused on (a) parent involvement in EIBI; (b) interventions to improve parent skills in an effort to improve child behavior; (c) sibling-mediated intervention; (d) family support practices; and (e) interventions to decrease family stress. This review suggests that these interventions and supports have contributed to positive parent–child, parent, and child outcomes. From this review of the literature, several issues for future research have emerged.

First, the studies reviewed here suggest that parent-directed EIBI may not result in outcomes as promising as those achieved through clinic-directed programs. These differential effects might be explained by differences in quantity and quality of one-to-one intervention and program administration (e.g., hiring, training, and supervising therapists). Future research evaluating parent-directed programs should evaluate procedures aimed at increasing the amount of intervention and mechanisms for increasing treatment fidelity. Also, comparisons of parent and clinic-directed programs of the same intensity and quality are lacking, preventing definitive conclusions about the outcomes of parent-directed EIBI programs. Future research should include studies comparing child outcomes from equivalent parent and clinic-directed EIBI programs. Moreover, parents participating in parent-directed EIBI programs may benefit in important ways that are not possible in clinic-based programs. Parents may benefit from their child's improved behaviors (e.g., communication, play and social skills) at home and increase their knowledge of their child's behaviors and ABA strategies, increased social support and respite (Grindle et al. 2009). Future research should include broader outcome measures, to gauge the impact of parent-directed EIBI on not only parent–child interactions and child behaviors, but also parent and family outcomes.

Second, currently utilized parent training procedures are often effective, but the heterogeneity of ASD, parent education and experience, and a family's resources and support system is likely to influence the success of parent training and subsequent parent-implemented intervention (Matson et al. 2009). Future research should systematically evaluate the child and family factors that influence the success of parent training. Additionally, the majority of parent training programs include multiple-intervention components (e.g., Lang et al. 2009). Identifying the core elements of parent training that contribute to skill acquisition, generalization, and maintenance may be essential to scaling up parent skills training where time intensive interventions are often negated by the lack of community funding, and family resources. Kaminski et al.'s (2008) meta-analysis of parent training program effectiveness for addressing the challenging behavior of young children (without developmental disabilities) found several components were associated with larger, positive effects on parenting behaviors and children's externalizing behaviors. Specifically, parent training was more effective when focused on (a) increasing positive parent–child interactions and emotional communication skills, (b) teaching parents the correct use of time out from positive reinforcement and the importance of consistent parenting behaviors, and (c) requiring parents to practice targeted skills with their child during training sessions (Kaminski et al. 2008). Future behavioral skills training research with parents of children with ASD should conduct component analyses to determine the contribution of individual training procedures to positive parent and child outcomes.

Third, typically developing siblings have been successfully involved in interventions targeting social, communication, and play skills as interventionists (Ferraioli and Harris 2011; Tsao and Odom 2006). However, conclusions regarding the effectiveness of sibling-mediated interventions for children with ASD are not yet possible due to the limited number of published studies. Given the potential benefits of including siblings of children with ASD in intervention efforts, future research should evaluate the effects of sibling-mediated interventions, including comparisons of sibling, peer, and parent-delivered interventions.

Fourth, interventions to reduce parent stress have consisted of interventions directed at children's challenging behaviors, parent education, and parental psychological functioning. The studies reviewed here suggest promising results in terms of reduced parent stress and improved psychological functioning. Future research should evaluate ways to meaningfully individualize interventions based on a parent's coping style, specifically tailoring interventions for mothers and fathers. Interestingly, the limited amount of research evaluating parent and child-related stress has focused on negative experiences and outcomes. However, a growing body of literature has reported positive experiences for parents of children with developmental disabilities, including ASD (Hastings and Taunt 2002; Kayfitz et al. 2010; Seltzer et al. 2001a). For example, Kayfitz et al. (2010) found that mothers of children with autism report more positive experiences than fathers and that these positive experiences may be related to lower levels of maternal stress. A focus on parents' positive experiences may identify novel interventions aimed at helping shield parents from the effects of stress and to reframe experiences as positive (Folkman and Moskowitz 2000; Tugade and Fredrickson 2004). Future research targeting parent stress should additionally focus on evaluating positive experiences of parents and siblings of children with autism to identify individual and family characteristics and attitudes that may contribute to improved well-being and positive child and family outcomes.

Finally, given the wide range of presenting issues requiring intervention and the different strengths and support needs presented by individual families, autism intervention delivery should be based on family-centered services and supports that consider the needs of each family from a family systems perspective (Dunst and Trivette 2009; Dunst et al. 1988, 1994;Trivette et al. 1986). Family-systems theory includes core components of family strengths, social systems, empowerment, social support and help-giving theories (Dunst and Trivette 2009;Trivette et al. 2010). From a family-systems model of intervention, practitioners use capacity-building, help-giving practices to (a) identify a family's concerns and priorities, (b) identify supports and resources to meet family needs, and (c) use existing family strengths and the development of new behaviors to obtain needed resources and supports to meet family needs (Dunst and Trivette 2009). These practices have been recently shown to affect parent, parent–child, and child behavior and functioning (Trivette et al. 2010) and incorporating a family-systems model of intervention into the provision of family and sibling supports might contribute to positive child, parent–child, and family outcomes. Future research should evaluate the effectiveness of family supports, including intervention efforts, when provided within a family-centered model.

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Management of General Medical Conditions

25

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Keywords

Comorbidity · Gastrointestinal · Food selectivity · Seizures

There is increasing awareness that children with autism spectrum disorder (ASD) have significant medical needs (Bauman 2010; Coury 2010). In this chapter, we will review the evaluation and management of common medical comorbidities in children with ASD: sleep disturbances, seizures, and gastrointestinal disorders. Evaluating these disorders in children with ASD may require greater attention to a parent's intuition that something is not right, a higher level of attention to subtle nonverbal clues from the child, and an appreciation that common medical disorders may present in uncommon ways. Because of the complexity, the primary care provider (PCP) may need to collaborate with other team members (educators, therapists, and other medical subspecialists) to establish a plan for evaluation and management of these conditions. Unfortunately, parents of children with ASD have difficulty accessing this type of interdisciplinary care within the current system of health-care delivery (Brachlow et al. 2007; Kogan et al. 2008; Liptak et al. 2006).

Two changing epidemiologic trends over the past 50 years are transforming the type of medical care required of pediatricians: the control of serious infectious diseases and advances in medical technology leading to survival of more children with serious medical conditions and developmental disabilities (Stein 2011). These two trends have resulted in a decreased need for acute evaluation of children with potentially serious infections and a greater need for visits that address ongoing needs of children with chronic conditions (Murphy and Carbone 2011). Currently, one in seven children in the USA (10.2 million) have special health-care needs (Kogan et al. 2009), and approximately 1 % of children have an ASD (Rice 2009). With this changing epidemiology of child health, a new concept of medical care for children with disabilities, "the medical home" (The Medical Home 2002), has emerged as a method to better address the needs of families of children with disabilities.

Rather than a building or location, the medical home represents a process of care that emphasizes ongoing care of chronic issues, rather than the traditional model of well visits and acute

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care. A cornerstone of this process of care is continuous access to a personal provider who is able to comprehensively address needs in a family centered, compassionate, and culturally sensitive manner (The Medical Home 2002). Ideally, the medical home serves as a headquarters for care that is coordinated and integrated within a larger community-based system of services. Within this new paradigm of health-care delivery, providers can better communicate with one another in order to develop a comprehensive treatment plan that is developed jointly by the treatment team and family (McPherson et al. 2004). There is evidence that this type of care yields better outcomes. Parents of children with ASD and other special health-care needs who have medical homes report better access to needed services, report less reliance on emergency and hospital-based care, feel a greater sense of partnership with their providers, and have a higher level of overall satisfaction with care (Cooley et al. 2009; Golnik et al. 2011; Strickland et al. 2009).

Despite the benefits, implementing the medical home model of care has been difficult. Currently only 25 % of children with ASD receive care within a medical home (Brachlow et al. 2007). Transitioning to a system that allows medical practices to offer longer visits to address ongoing medical needs and care coordinators who work with families between medical visits is a process with many barriers. Several recent pieces of federal legislation address some of the barriers of providing adequate reimbursement for medical home activities for children with disabilities (CHIPRA quality demonstration grants 2010; Farrell et al. 2011).

Success depends on the system level changes that are needed to implement the medical home and on medical providers that are committed to enter into trusting partnerships with families of children with ASD. While our understanding of ASD and associated medical conditions will continue to advance, the benefit of these advances will only be realized if our system of health-care delivery moves toward those ideals embodied within the medical home model of care.

Gastrointestinal Disorders in Children with ASD

Introduction

As the awareness of ASD has risen dramatically over the past decade, medical providers have heard divergent viewpoints regarding gastrointestinal disorders in children with ASD. One infamous example occurred in the late 1990s, when a British physician claimed that changes in the gastrointestinal tract (a “leaky gut”) caused by the measles, mumps, rubella (MMR) vaccine given to 1-year-olds actually caused ASD. Despite a subsequent retraction of the study after revelations of serious methodological flaws and many epidemiologic studies showing lack of cause, many parents continue to refuse MMR and other vaccines because of concerns about autism (Chatterjee and O’Keefe 2010; Gerber and Offit 2009).

Due to this controversy, providers who care for children with ASD may have lost sight that common gastrointestinal disorders affecting children with typical development also occur in children with ASD with at least the same frequency. The pendulum has now swung in this direction, with an expert panel encouraging adaptation of existing guidelines for evaluation of gastrointestinal problems in children without ASD (Chronic Abdominal Pain in Children 2005; Hepatology and Nutrition 2006) to those with ASD (Buie et al. 2010a, b).

In this section, we will review recent research suggesting a high prevalence of gastrointestinal problems in children with ASD and the current consensus on evaluation and management of these disorders. We will also review two related topics that are of great interest to parents and providers: food selectivity and the gluten-free, casein-free (GFCF) diet. While there is still much to be learned about gastrointestinal disorders in children with ASD, it is clear that effective treatment can alleviate gastrointestinal symptoms and more broadly result in improvements in overall function and quality of life.

Definition of Gastrointestinal Disorders in Children

Gastrointestinal disorders in children encompass a wide variety of symptoms and conditions of the gastrointestinal tract. The definitions of seven common gastrointestinal problems seen in children with and without ASD are as follows:

- *Chronic abdominal pain (CAP)* is defined as at least three pain episodes over the preceding 3 months that adversely affect the function of the child. Most causes of CAP are functional, meaning that the pain occurs in the absence of an anatomic abnormality, inflammation or tissue damage. Functional causes of abdominal pain have been further categorized as functional dyspepsia, irritable bowel syndrome, abdominal migraine, and functional abdominal pain syndrome (Chronic Abdominal Pain in Children 2005).
- *Constipation* is defined as a delay or difficulty in the passage of stool (i.e., infrequent or hard stools) for greater than 2 weeks. Most cases of constipation are functional in nature but organic causes, such as hypothyroidism and spinal cord abnormalities, can also cause constipation (Hepatology and Nutrition 2006).
- *Encopresis* occurs when a child with constipation and fecal impaction can no longer voluntarily withhold the passage of stool. Soft stool from above the fecal impaction “oozes” around the impaction and leaks out in frequent smears or in larger amounts. These stools frequently are liquid or at least softer in consistency than formed stools, leading some caregivers to mistakenly believe the child has diarrhea (Hepatology and Nutrition 2006).
- *Chronic diarrhea* is defined as loose stools that persist for 2 weeks or longer. Diarrhea of shorter duration is generally caused by self-limited viral infections but chronic diarrhea can be due to bacterial, fungal, or parasitic infections, immunodeficiency, abnormal immune responses, lactase deficiency, malabsorption syndromes, inflammatory diseases, and functional causes (benign and related to dietary factors). (Buie et al. 2010b).
- *Gastroesophageal reflux disease* (GERD) results from complications of passage of stomach contents into the esophagus (Rudolph et al. 2001).
- *Lactose intolerance* is a clinical syndrome of one or more of the following: abdominal pain, diarrhea, nausea, flatulence, and/or bloating after the ingestion of lactose-containing food substances (Heyman 2006).
- *Celiac disease* is an autoimmune condition triggered by exposure to gluten and related proteins. Beyond gastrointestinal symptoms, children with celiac disease may experience extra intestinal manifestations, such as short stature, dental enamel hypoplasia, arthritis, and neuropsychiatric symptoms (Zawahir et al. 2009).

Epidemiology of Gastrointestinal Disorders in Children with ASD

Estimates of the prevalence of gastrointestinal disorders in children with ASD vary widely, from as low as 9 % (Black et al. 2002), to as high as 70 % (Valicenti-McDermott et al. 2006). This variation is probably due to the heterogeneous nature of ASD, the lack of universally agreed upon definitions of gastrointestinal disorders, and differences in study methodology. There is, however, general agreement that gastrointestinal disorders are at least common and probably more prevalent in children with ASD than in typically developing peers (Buie et al. 2010a). One study that compared children in the same family with and without autism demonstrated that the children with autism were 14 times more likely than their typically developing siblings to have parent reported gastrointestinal problems. The most commonly reported gastrointestinal disorders were constipation (20 %) and diarrhea (19 %), compared with 4 % and 2 % respectively in siblings with typical development (Wang et al. 2011).

Etiology of Gastrointestinal Disorders in Children with ASD

Although a subject of ongoing debate, current evidence suggests that the etiologies and pathophysiology of gastrointestinal disorders in children with and without ASD are similar. While there may be an association, there is no evidence that gastrointestinal issues actually cause autism (Buie et al. 2010a).

The possibility of autism-specific gastrointestinal pathology continues to be an area of active research. Although several studies have suggested that abnormal gastrointestinal permeability may indeed exist in some children with ASD (de Magistris et al. 2010; D'Eufemia et al. 1996), the findings have not been correlated with either the presence of gastrointestinal disorders or with symptoms of ASD. Another recent study suggested differences in the gastrointestinal microflora between children with ASD and children with typical development (Adams et al. 2011; Williams et al. 2011) but if and how these differences in the proportion of beneficial bacteria lead to gastrointestinal disorders or symptoms is not clear. Genetic factors, such as disrupted signaling of a gene involved in gastrointestinal repair and motility (MET) and altered expression of an intestinal transcription regulator (CDX2) have been identified as potential contributors to gastrointestinal disorders in some children with ASD (Campbell et al. 2009; Williams et al. 2011). Another line of research suggests that gastrointestinal dysfunction in some children with ASD involve abnormal immune system responses. For example, in children with ASD and a family history of autoimmune diseases, gastrointestinal symptoms were observed more frequently in a subpopulation with language regression (Valicenti-McDermott et al. 2008). Other studies involving small numbers of patients have reported contradictory evidence of an inflammatory process in the gut mucosa in children with ASD (Ashwood et al. 2004; DeFelice et al. 2003; Jyonouchi et al. 2005).

It is possible that these various lines of research will lead to more specific approaches to the evaluation and treatment of gastrointestinal disorders in children with ASD. At the present time, however, the clinical approach to gastrointestinal disorders in children with ASD assumes that their pathology and etiology are the same as those of gastrointestinal disorders in children without ASD.

Evaluation of Children with ASD for Gastrointestinal Problems

A child with ASD suspected of having a gastrointestinal disorder should have the same thorough evaluation as the child without ASD (Buie et al. 2010a). Providers may need to adapt existing guidelines for the evaluation of suspected gastrointestinal disorders to address the unique features of children with ASD. The evaluation begins with a thorough history of the presenting symptoms, followed by a physical examination. Eliciting a history about the presence, timing, severity, location, and relieving and exacerbating factors of gastrointestinal symptoms can be challenging in children with ASD. While some children with ASD may be able to communicate their symptoms, in others with significant communication deficits, abdominal discomfort may produce symptoms that appear completely unrelated to the gastrointestinal tract (such as self-injurious behavior, agitation, and sleep difficulty) or with subtle nonverbal clues such as cradling the abdomen by laying over furniture, tapping on the chest, frequent throat clearing, or chewing on clothes (Buie et al. 2010a). (Table 25.1) The history should also include information about the frequency of bowel movements, the consistency/size of stools, the presence of vomiting or blood in the stools, and whether the child experiences pain with defecation. In response to the pain related to constipation, some children will engage in stool withholding behavior. Caregivers may report that children with ASD contract their gluteal muscles, stiffen or cross their legs, or hide when attempting to withhold stooling. Questions about amount of water, dietary fiber, and intake of medications that slow intestinal motility can aid in determining risk factors for constipation. A thorough family history may also prompt con-

Table 25.1 Behaviors that may be markers of abdominal pain or discomfort in individuals with ASD (Adapted from Buie 2010a)

Vocal behaviors	Motor behaviors[a]	Changes in overall state
Frequent clearing of throat, swallowing, tics, etc	Facial grimacing	Sleep disturbances: difficulty getting to sleep, difficulty staying asleep
Screaming	Gritting teeth	Increased irritability (exaggerated responses to stimulation)
Sobbing "for no reason at all"	Wincing	Noncompliance with demands that typically elicit an appropriate response (oppositional behavior)
Sighing, whining	Constant eating/drinking/swallowing ("grazing" behavior)	
Moaning, groaning	Mouthing behaviors: chewing on clothes (shirt sleeve cuff, neck of shirt, etc), pica	
Delayed echolalia that includes reference to pain or stomach (eg, child says, "does your tummy hurt?" echoing what mother may have said to child in the past)	Application of pressure to abdomen: leaning abdomen against or over furniture or kitchen sink, pressing hands into abdomen, rubbing abdomen	
Direct verbalizations (eg, child says "tummy hurts" or says "ouch," "ow," "hurts," or "bad" while pointing to abdomen)	Tapping behavior: finger tapping on throat	
	Any unusual posturing, which may appear as individual postures or in various combinations: jaw thrust, neck torsion, arching of back, odd arm positioning, rotational distortions of torso/trunk, sensitivity to being touched in abdominal area/flinching	
	Agitation: pacing, jumping up and down	
	Unexplained increase in repetitive behaviors	
	Self-injurious behaviors: biting, hits/slaps face, head-banging, unexplained increase in self-injury	
	Aggression: onset of, or increase in, aggressive behavior	

A functional behavioral assessment would be useful in interpreting these behaviors

[a] Motor behaviors also may be markers of pain or discomfort arising in other parts of the body

sideration for certain disorders, such as food allergy or celiac disease. Having the family keep a dietary record might also help identify an offending agent for certain gastrointestinal symptoms such as excessive intake of fruit juice leading to chronic diarrhea or identifying certain food as likely allergens.

Lastly, the history should always include questions that alert the clinician for more serious pathologic disorders. These "alarm" signs and symptoms include weight loss, gastrointestinal bleeding, prolonged or persistent vomiting, prolonged diarrhea, localized abdominal pain, and unexplained fever. The presence of these symptoms should prompt further evaluation for organic causes (Buie et al. 2010b).

The physical exam may also provide critical information regarding the cause of the possible gastrointestinal disorder. For example, a child with constipation might have palpable stool within the left lower quadrant of the abdomen, and a rectal exam might reveal large amounts of stool within the rectal vault. An abdominal and rectal exam can be challenging to perform on children with ASD because of the anxiety and tactile defensiveness that some children display in the clinical setting. Because children with ASD rely on predictability it may help to explain the components of the exam in a developmentally appropriate way to the child before starting. Parents can also be encouraged to bring along reinforcers that can be given upon completion of the exam. During the exam, using techniques such as “countdowns” can help the child clearly understand when portions of the exam will begin and end. A careful neurologic examination that evaluates muscle tone, strength, and reflexes can provide important clues for the organic etiologies of chronic constipation, such as tethered spinal cord. The physical exam should always include review of growth and nutritional status by calculating the body mass index or weight for length. Being underweight is an important finding and may trigger a referral to a nutritionist and pediatric gastroenterologist to assess the adequacy of caloric intake and consideration of further workup for inflammatory, malabsorptive, or other organic disorders.

Further testing is based on the findings from the history and physical exam but may include celiac disease screening (total IgA and tissue transglutaminase), food allergy testing (IgE-based serum tests or referral to an allergist for skin prick testing), stool samples for bacteria and parasites, a lactose breath test, quantitative fecal fat, stool alpha-1-antitrypsin and guaiac testing for the presence of blood in the stool. Some of these tests may be difficult to obtain from children with ASD. Rather than forgoing a needed test, an upper or lower endoscopic exam under anesthesia may be performed by a gastroenterologist who can obtain tissue samples to assess for many of the disorders listed above.

Management of Common Gastrointestinal Problems in Children with ASD

Treatment of gastrointestinal disorders in children with ASD should be based, if possible, on an identified cause. However, when the history and physical exam are highly suggestive of a particular diagnosis and there are no alarming signs, an empiric trial of a medication or dietary modification for a particular gastrointestinal disorder is warranted, rather than first performing confirmatory tests that may be more invasive. For example, a child that has symptoms suggestive of GERD could receive a 4-week trial of a proton-pump inhibitor without undergoing endoscopy or a pH probe. In the case of chronic abdominal pain that appears to be triggered by lactose containing foods, a 2-week trial of a lactose free diet is reasonable. If the child does not respond to the trial, further invasive or noninvasive testing should be undertaken under the guidance of a pediatric gastroenterologist (Buie et al. 2010a) (Table 25.2).

Constipation and Encopresis The treatment of constipation and encopresis in children with ASD deserves further explanation and demonstrates the benefit of an interdisciplinary team approach. Children with ASD have a higher risk of functional constipation for several reasons. First, the sensory processing difficulties experienced by many children with ASD (Kern et al. 2006), can cause increased sensitivity to the discomfort of stool passage and lead to stool withholding behaviors. Second, children with ASD frequently take medications for associated disorders that have anticholinergic properties that slow intestinal motility (Rosenberg et al. 2010). Third, anxiety is a common psychiatric comorbidity that may lead children to develop phobias about using toilets away from the predictable environment of their home, further contributing to voluntary stool withholding (Leyfer et al. 2006). Lastly, the selective diets of some children with ASD may lack adequate fiber, leading to hard stools (Herndon et al. 2009). Constipation without adequate treatment may lead to fecal impaction and encopresis or repeated involuntary fecal soiling.

If there is fecal impaction and encopresis the first step in treatment is disimpaction (Hepatology and Nutrition 2006). This can be achieved with oral medications, such as polyethylene glycol, or enemas over 1–3 days. Many children, including those with ASD, may not tolerate enemas or drinking the large volumes of medication required and will benefit from nasogastric adminis-

Table 25.2 Diagnostic evaluation of gastrointestinal symptoms and disorders in individuals with ASD (Adapted from Buie 2010a)

Symptom	Possible associated gastrointestinal disorder	Definition	Diagnostic evaluations to be considered
Sleep disturbance	GERD	Parental/provider report	(1) Diagnostic trial of proton-pump inhibitor; (2) pH probe, EGD
Self-injurious behavior, tantrums, aggression, oppositional, behavior	Constipation, GERD, gastritis, intestinal inflammation	Parental/provider report	(1) Abdominal radiograph; (2) Diagnostic trial of proton-pump inhibitor or PEG 3350; (3) pH probe, EGD, colonoscopy
Chronic diarrhea	Malabsorption, maldigestion	loose stools daily for >2 wk	(1) Stool analysis for occult blood, enteric pathogens, ova/parasites (*Eiardia* or *Cryptosporidium*), *Clostridium difficile*, (2) Consider PEG 3350 if overflow diarrhea is a possibility; (3) Lactose breath test (or measure lactase-specific activity), EGD, colonoscopy
Straining to pass stool, hard or infrequent stool	Constipation	<2 hard stools per week (Bristol stool score)	(1) Abdominal radiograph to look for fecal impaction; (2) Diagnostic trial of PEG 3350
Perceived abdominal discomfort: pressing abdomen, holding abdomen and crying, problem behaviors related to meals	Constipation, GERD, intestinal inflammation. malabsorption, maldigestion		(1) Diagnostic trial of proton-pump inhibitor or PEG 3350; (2) Abdominal radiograph; (3) Lactose breath test (or measure lactase-specific activity); (4) pH probe, EGD, colonoscopy
Flatulence and/or bloating	Constipation, lactose intolerance, enteric infection with *Eiardia* or *Cryptosporidium*		(1) Abdominal radiograph; (2) Diagnostic trial of PEG 3350 or lactose restriction; (3) Lactose breath test or EGD (measure lactase-specific activity)
Any or all of the above	FAP, IBS	FAP: abdominal pain without demonstrable evidence of anatomic, metabolic, infectious, inflammatory, neoplastic, or other pathologic condition IBS: FAP associated with alteration in bowel movements	(1) Behavioral soothing; (2) Diet enhancements with fruits, fiber, sufficient fluids; (3) Increase in routines for sleep and toilet time

EGD esophagogastroduodenoscopy, *PEG* polyethylene glycol

Table 25.3 Medications for use in treatment of constipation in children. (Adapted with permission from Constipation Guidelines Committee of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. J Pediatr Gastroenterol Nutr. 2006:43 (3):e1–e13.)

Medication	Dosage	Comments
Lactulose (70 % solution)	1–3 mL/kg per d in divided doses	Well tolerated
Sorbitol (70 % solution)	1–3 mL/kg per d in divided doses	Similar to lactulose but less expensive
Magnesium hydroxide (400 mg/5 mL, 800 mg/5 mL, or tablets)	3 mL/kg per d	Monitor for Mg toxicity, hypophosphatemia, hypocalcemia
Magnesium citrate (liquid, 16.17 % Mg)	< 6 y of age: 1–3 mL/kg per d; 6-12 y of age: 100–150 mL/d in single or divided doses; > 12 y of age: 150–300 mL/d in single or divided doses	Monitor for Mg toxicity, hypophosphatemia, hypocalcemia
PEG 3350	1–1.5 g/kg per d for 3 d; maintenance: 1 g/kg per d(usual dose 17 g/d)	Palatable (can be dissolved in most fluids); not approved for use in infants
Phosphate enemas	< 2 y of age: to be avoided; ≥ 2 y of age: 6 mL/kg up to 135 mL	May be psychologically traumatic; may damage rectal wall; may cause abdominal distention or vomiting; tetany with hyperphosphatemia/hypocalcemia; avoid if renal disease is present
PEG electrolyte solution	For disimpaction: 25 mL/kg per h (maximum: 1000 mL/h) via nasogastric tube until clear; maintenance: 10 mL/kg per d	Taste is an issue; may cause nausea, bloating, cramps, vomiting
Mineral oil	< 1 y of age: not recommended; > 1 y of age: maintenance 1–3 mL/kg per d	Safe alternatives are available; should be used only if other agents fail; lipoid pneumonia if aspirated; leakage of stool; concern about impairing absorption of fat-soluble vitamins has not been substantiated clinically
Senna (syrup, 8.8 mg sennosides per 5 mL)	2–6 y of age: 2.5 mL/d; > 12 y of age: 5–15 mL/d	May cause permanent nerve or muscle damage, hepatitis, melanosis coli
Bisacodyl suppository (10 mg)		May irritate rectal mucosa
Bisacodyl tablets (5 mg)		Abdominal pain, diarrhea, hypokalemia
Glycerin suppositories		Minimal adverse effects except for stress caused from insertion

Mg magnesium

tration of medications or manual disimpaction in an inpatient setting. This requires an experienced inpatient team with expertise in the needs of children with ASD.

After disimpaction, the goal of maintenance treatment is painless passage of 1–2 soft stools daily. The maintenance phase of treatment involves daily use of medications (osmotic agents, lubricants, and stimulants; Table 25.3), dietary modifications, and behavioral supports (Hepatology and Nutrition 2006). Maintenance medications should be continued daily for 6 months to avoid relapses. Children with ASD who are sensitive to certain textures may refuse some medications (Williams et al. 2000), so it is important to find a medication in the form of a liquid suspension, chewable tablet, or traditional tablets that the child will accept. The child should remain on a high fiber diet (5 g + the age of the child per day; Tabbers et al. 2011). In children with ASD who refuse fiber-containing foods, a variety of over-the-counter fiber supplements are available. Adequate water consumption should be encouraged and, because caffeinated beverages decrease the water content in stools, they should be discouraged. In addition to many other benefits, regular exercise may be beneficial in treating and preventing constipation (de Oliveira and Burini 2009). Unfortunately, children with ASD and other disabilities have fewer opportunities to participate in regular recreational activities. Clinicians should encourage the family with an "exercise prescription" and assist families in locating appropriate adaptive recreational programs in the community (Murphy and Carbone 2008).

Lastly, children with ASD may benefit from behavioral supports to maintain regularity with bowel movements. Caregivers can utilize a reward system to encourage children to sit on the toilet after meals. A calendar with stickers for sitting and for stool successfully passed into the toilet serves not only as a means of reward for the child but also helps caregivers and clinicians to accurately track stool frequency (Hepatology and Nutrition 2006). It is important for the child to feel secure while sitting on the toilet and that their feet can touch the floor or a stool to facilitate making a valsalva movement. It is also important to be cognizant of sensory issues such as the feel of the toilet seat or the loudness of flushing the toilet. Consultation with a behavioral therapist may help successfully implement such a system in cases when the child is unmotivated to comply. Coordinating efforts with the child's educational team can be helpful in the implementation of a consistent strategy throughout the child's day. Successful treatment of constipation in children with ASD requires a motivated family and an interdisciplinary approach. Regular follow-up visits help clarify the treatment plan and help families succeed. This clinician has utilized a "constipation action plan" as a way to create a family-centered treatment plan that can be updated and revised at subsequent visits.

If conservative therapies for functional constipation are not successful further testing for organic causes of constipation and referral to a pediatric gastroenterologist are indicated according to guidelines published by the North American Society for Pediatric Gastroenterology (Hepatology and Nutrition 2006).

Food Selectivity in Children with ASD

Caregivers of children with ASD often describe their children as "picky eaters" (Bandini et al. 2010; Lockner et al. 2008; Nadon et al. 2011; Provost et al. 2010). *Food selectivity* encompasses a number of different behaviors such as picky eating, frequent food refusals, limited repertoires of foods, excessive intake of a few foods, and selective intake of certain food categories. This condition should be considered when a caregiver reports intakes of fewer than 20 different foods (Cermak et al. 2010). Despite methodologic limitations of studies, food selectivity is believed to be more common in children with ASD than in typically developing peers (Cermak et al. 2010). Parents report that factors such as food texture, appearance, taste, smell, and temperature are the principle influences of food acceptance in children with ASD (Bennetto et al. 2007; Provost et al. 2010; Williams et al. 2000).

The Etiology of Food Selectivity in Children with ASD

While an insistence on the same type of food or having rigid adherence to a narrow range of feeding behaviors could be consistent with the core features of ASD, food selectivity in some children with ASD may be causally related to a common associated condition known as *sensory processing disorder*. Although not considered a core symptom, this condition, defined as unusual or unexpected responses to environmental and sensory stimuli that adversely affect life activities, has been strongly associated with ASD (Kern et al. 2006). Children with tactile defensiveness, who have a negative response to being touched or hugged may be particularly prone to food sensitivity (Smith et al. 2005). Clinicians should also be alert to the possibility of one of the gastrointestinal disorders discussed earlier, such as GERD, constipation or food allergy as an underlying cause of food selectivity. Any of these gastrointestinal conditions may make the experience of eating less pleasurable and result in a child becoming more food selective.

Food Selectivity and Nutritional Deficiencies

Despite the issue of food selectivity, it is unclear if children with ASD as a group have higher rates of nutritional deficiencies compared with typically developing peers. Some studies have found significantly lower intakes of certain macro and micronutrients (Herndon et al. 2009; Schreck et al. 2004b), while others have not (Levy et al. 2007). Significant illnesses related to nutritional deficiencies, such as scurvy from vitamin C deficiency and vision loss related to hypovitaminosis A and vitamin B12 deficiency, have been reported among children with ASD and food selectivity (Bruins et al. 2011; Duggan et al. 2007; Pineles et al. 2010; Tang et al. 2011). Food selectivity in children with ASD may also place them at risk for becoming underweight and overweight (Curtin et al. 2010; Hebebrand et al. 1997). Thus, although the risks of nutritional problems among children with ASD as a group are uncertain, it is clear that those with food selectivity are at increased risk.

Management of Food Selectivity in Children with ASD

Children with food selectivity, especially those with abnormalities in growth parameters (underweight, overweight, or significant changes in growth rate), those with symptoms of dysphagia (difficulty in swallowing) or a history of aspiration pneumonia, and those with symptoms of food allergy should be evaluated by an interdisciplinary team. A registered dietician can assess nutrient intake, the risk for nutritional deficiencies and make recommendations about nutritional support with regards to caloric intake and vitamin and mineral supplementation. An allergist may recommend appropriate allergy testing (skin testing, measurement of allergen-specific IgE levels) in those children in which food allergy is suspected. A feeding therapist (generally within the discipline of occupational or speech therapy) can help to identify the underlying cause of food selectivity with specialized studies of swallowing function and evaluation of sensory processing difficulties. Based on the underlying cause a treatment plan can be developed. In the case of sensory processing difficulties, the feeding therapist may work with caregivers to identify alternative foods or food preparation strategies that slowly increase the tolerability of a wider variety of foods that meet the child's nutritional needs. Gradual desensitization can also be helpful. Behavioral therapists can use behavioral modification techniques to motivate the child to accept new foods, and an occupational therapist may be able to modify the feeding environment to reduce excess stimuli that may be increasing mealtime stress (Cermak et al. 2010).

The Gluten-Free, Casein-Free (GFCF) Diet in Children with ASD

The GFCF diet is a commonly used complementary and alternative treatment (CAM) in children with ASD (Wong and Smith 2006) and has been promoted to address both the core symptoms of ASD and associated gastrointestinal symptoms. Gluten is a protein found in wheat, barley, and rye; casein is a protein found in dairy products. The rationale for this restrictive diet is based on a hypothesis of abnormal intestinal permeability and incomplete breakdown of the proteins in gluten and casein. This incomplete breakdown is said to lead to the formation of opioid like peptides that then act on the nervous system to contribute to the symptoms of ASD. This hypothesis has not been proven (White 2003). Interest in the GFCF diet began in the 1960s as a treatment for schizophrenia when researchers noted a decrease in hospital admissions for schizophrenia during World War II when there was a concurrent decrease in wheat consumption (Dohan 1966). While one of the first randomized trials of the GFCF diet in children with ASD was promising (Knivsberg et al. 2002), a subsequent more rigorous randomized, double-blind, crossover designed study showed no significant improvements in the core symptoms of ASD (Elder et al. 2006).

Providers who care for children with ASD should expect questions from families about the GFCF diet. Presently there is a need for larger-scale studies to assess if children with ASD benefit from this diet (Millward et al. 2008). Providers should review the challenges in implementation with interested families. These include increased food related expenses, the extra time, effort, and commitment required for food preparation, the potential for nutritional deficiencies (e.g., vitamin D and calcium), and worsening food refusal in an already selective eater (Elder 2008). In order to ensure the safest implementation of the GFCF diet, providers may wish to refer interested families to a registered dietician.

Because the GFCF diet is considered to be generally safe, experts in CAM have encouraged providers to support families who choose implementation and to encourage a means to objectively evaluate outcomes (Akins et al. 2010). Providers may wish to encourage an "N of 1 trial" in which the family chooses the target symptoms or outcomes they wish to evaluate in their child before and after implementing the GFCF diet. With the use of a tool such as a change monitoring log, the family or other members of the treatment team can systematically record the frequency and severity of target symptoms and review this periodically with the provider at follow-up visits (Golnik et al. 2011).

Seizures and Epilepsy in Children with ASD

Introduction

ASD and seizures/epilepsy are complex, heterogeneous conditions; therefore, the management of children with both conditions may be challenging. Both can result from conditions such as tuberous sclerosis, or they can by themselves be diagnosed (e.g., idiopathic autism and absence epilepsy). Much of the research done in the past attempted to include patient groups that seemed at the time to be homogeneous but are now recognized as including patients with autism and genetic syndromes associated with epilepsy (e.g., Angelman and Rett syndromes), making conclusions difficult.

Definition of Seizures and Epilepsy

Seizures are defined as events resulting from paroxysmal, excessive electrical discharges in the brain that cause a variety of clinical manifestations. Epilepsy is a term used when an individual has recurrent seizures.

Electroencephalographic Abnormalities Without Clinical Seizures in Children with ASD

Individuals with ASD have, compared with the general population, an increased incidence of electroencephalographic abnormalities without clinical manifestations of seizures. These include paroxysmal bursts of spike, spike/wave, polyspike, polyspike/wave, and localized spikes in central, temporal, and parietal regions, similar to those seen in the benign focal epilepsies of childhood. The significance of electroencephalographic abnormalities in individuals without clinical seizures are not well understood but may be viewed as evidence of central nervous system dysfunction (Spence and Schneider 2009).

Epidemiology of Epilepsy in Children with ASD

Individuals with ASD have a higher incidence of seizures/epilepsy than the general population. Although rates vary widely depending on inclusion criteria for patients, epilepsy is found in 6–46 % of individuals with ASD compared with a lifetime risk for epilepsy in the general population of 3 % (Spence and Schneider 2009). Individuals with ASD who also have cerebral palsy or intellectual disability are on the high end of this range, while individuals with ASD without these conditions have a much lower prevalence of epilepsy (2–8%) (Tuchman and Rapin 2002). Individuals with ASD also have a higher percentage of electroencephalographic abnormalities without clinical seizures, although the significance of this is unclear (Tuchman and Rapin 2002).

There are two age peaks for epilepsy in children with ASD, early childhood and adolescence. As many individuals with ASD and seizures have long-term, possibly life-long epilepsy, prevalence increases as the age of the population being studied increases (Tuchman and Rapin 2002). Many seizure types have been described in individuals with ASD (Spence and Schneider 2009) although some authors feel that complex partial seizures are the most common (Hara 2007). The regression in language and social interaction observed in approximately one-third of children with ASD (Levisohn 2007) appears to occur at the same frequency whether or not that child has epilepsy, but a regression in verbal abilities may signal a more severe clinical course in terms of cognitive and behavioral outcomes (Shinnar et al. 2001b).

Not surprisingly, individuals with ASD and epilepsy often have a diminished quality of life compared with individuals with only one of these conditions (Shinnar et al. 2001). Individuals with ASD and epilepsy score lower on social maturity scales and are more likely to be prescribed psychotropic medications than individuals without seizures (Hara 2007). Individuals with both conditions are also more likely to have intellectual disability than individuals with ASD alone (Tuchman and Cuccaro 2011). Lastly, it is unclear whether individuals with ASD and seizures begin with a more severe underlying brain disorder than those with ASD alone or whether the presence of epilepsy leads to a further decline in function.

Evaluation of Seizures in Children with ASD

Is it a seizure? The first question in any child with a seizure-like event is whether the noted event is a true epileptic seizure. This distinction is especially important in a child with ASD who may have stereotypies such as hand-flapping, other repetitive motor behaviors, or behavioral events such as rage or aggression. These and symptoms such as daydreaming, syncope, and night terrors may be misinterpreted as seizures. Some studies suggest that non-epileptic events are misdiagnosed as seizures 30% of the time; such misdiagnoses may expose individuals to unnecessary procedures or medications (Perrig and Jallon 2008).

To address the question of whether or not the event of concern is a seizure, a comprehensive history of the event(s) that might have been a seizure(s) needs to be elucidated. Is this event(s) predictable and stereotypical? Does it occur with anxiety or anger? If so, the event(s) are unlikely to be caused by seizure activity. It may be difficult to be certain at the initial evaluation whether the event was a seizure or not, it is often wise to have the parents monitor for subsequent similar events, videotape them, and keep an event journal. It may sometimes be useful to perform a long-term electroencephalogram (EEG) with video monitoring in order to catch the event at the same time as the EEG tracing. An event not accompanied by epileptiform EEG abnormalities is not likely to respond to antiepileptic medications. If the events being questioned are staring spells, the parents should be asked to touch and speak to the child during the episode; if the staring stops with this attention, a seizure is unlikely. Parents should also be asked to look for interruptions in activity (e.g., drinking a glass of water, walking across a room). If such interruptions are noted, the staring spells are more likely to be seizures. Environmental triggers should be noted carefully. Many children with seizures are more likely to have them if they are tired or ill, and on awakening from sleep. If there is uncertainty, it is best to acknowledge that and to continue to work with the parents until there is some clear understanding of whether an event is epileptic or not (Beach and Reading 2005). In a situation where it is not clear whether the child is having seizures or not, it is unlikely that getting an EEG will resolve the problem. As noted above, large proportion of children with ASD have abnormal EEGs (Spence and Schneider 2009). Conversely, a child with definite seizures may have a normal EEG. The child should instead be followed closely clinically. Sometimes the question of seizures comes from the school or therapists. If so, they need to be engaged in tracking events as well. Follow-up visits to discuss the journal of events or to view videos of the events should be scheduled before the family leaves the office to ensure that the possibility of seizures continues to be addressed. If the issue remains uncertain, a referral to a pediatric neurologist may be helpful in reaching a conclusion concerning the nature of the event (Deacon et al. 2003).

What kind of seizure is it? Once the event has been determined to be a seizure, understanding the type of seizure will guide evaluation and choice of medication. Caregivers should be asked to identify, if they can, where in the body an event that may be a seizure started; for instance, eyes beating to the left before jerking begins. A brief description of seizure types follows; a more extensive review of seizure classification has been previously published (Tuxhorn and Kotagal 2008).

Focal onset seizures (also called localized or partial seizures) start in one part of the body. Examples of focal onset seizures include: a seizure that starts with hand jerking, tingling on one side of the body, or a sense of fear. Focal onset seizures occur in children of all ages and may be difficult to diagnose and treat. Because these seizures may be associated with focal brain pathology (e.g., stroke or tumor), neuroimaging is almost always indicated. Seizures with focal onset before generalization are classified as *focal seizures with secondary generalization,* and for purposes of evaluation and treatment should be treated as focal seizures.

Generalized seizures begin with widespread manifestations, caused by widespread electrical dysfunction of the entire cortex. Some types of generalized seizures include:

- **Absence seizures** appear as a sudden impairment in consciousness often associated with eye blinking, staring, and other minor facial movements. There is abrupt interruption of preceding activities, but the child does not fall down or have a convulsion. They may last from a few seconds to a minute and typically occur multiple times per day with abrupt onset/termination and minimal, if any, postictal manifestations.
- **Atypical absence seizures** are most common in children with neurodevelopmental disabilities. Atypical absence seizures have gradual onset and termination, cyclic frequency, and are more prolonged or pronounced than typical absence seizures. The EEG pattern of these seizures is similar to that of absence epilepsy but has a slower frequency and is not as distinctive.
- **Myoclonic seizures** are lightning-quick limb or body jerks, either unilateral or bilateral, usually without impairment of consciousness.
- **Tonic-clonic seizures** (formerly known as grand mal seizures) generally involve tonic posturing (sustained contraction of muscles) followed by clonic activity (alternating contraction and relaxation of muscles in a rhythmic fashion), typically with sudden onset of increased truncal tone that causes the patient to cry out with forced expiration. Incontinence after the spells, as sphincter muscles relax, and postictal impairment of consciousness are common.
- **Atonic seizures** (also called "drop attacks") result in a sudden loss of all muscle tone, causing the patient to fall to the ground, often with injury.

Specific Tests in the Evaluation of Seizures in Children with ASD

Seizures may be either a symptom of an underlying disease (e.g., meningitis, tuberous sclerosis) or a disease diagnosis as in idiopathic generalized epilepsy. It is important to rule out any underlying cause for the seizures and to garner as much information as possible since this will often be helpful in treatment choice. Most children with an ASD and seizures should be referred to pediatric neurology at least to initiate management. The medical home and the specialist should clarify who will be assuming ongoing care, which will depend on the comfort level of the pediatrician.

Looking for underlying conditions A full history and physical exam should be performed in every child with new onset seizures. This should include a Wood's lamp exam for skin lesions suggestive of tuberous sclerosis. The clinical history of the event as well as the physical exam should be used to determine the need for any additional workup. For example, a stiff neck and fever would suggest the need for a lumbar puncture; prolonged vomiting episodes might suggest the need for further tests to screen for a metabolic disorder (Hirtz et al. 2000). Children with a new onset seizure disorder and a normal physical and neurologic exam do not need further blood tests.

Electroencephalogram An EEG (standard wake and sleep; non-sedated if possible) should be performed in all individuals with probable clinical seizures before or at the time of a referral to pediatric neurology. Some individuals with an ASD may be unable to stay still while the EEG electrodes are being placed on their scalps and for the actual EEG monitoring period. If this is the case, an EEG with sedation may be necessary. However, as EEGs performed under sedation can be difficult to interpret and many sedative agents increase brain activity in the beta range (commonly 18–25 Hz), this should be discussed with the pediatric neurologist. If a standard EEG does not provide enough information, additional EEG testing may be ordered by a pediatric neurologist, including long-term video monitoring/EEG. EEG results will be used to decide whether a magnetic resonance imaging (MRI) should be performed (if there is a localized source for seizures seen on EEG) and what medication is most likely to be helpful.

Brain imaging Brain imaging is not recommended unless the seizure had an obvious focal beginning, (e.g., eyes beating to the left before a generalized seizure), the neurologic exam is abnormal, or if the EEG shows a localized focus of epileptiform activity (Hirtz et al. 2000). When necessary, imaging should be MRI, not computed tomography (CT) as the picture of the brain obtained from MRI is much better than that obtained by CT and there is no radiation exposure. Many children with ASD will need sedation for this, whatever their age as they might have difficulty staying still for the 30–45 min necessary to perform the MRI scan.

Genetics Children with ASD and seizures, particularly if there are dysmorphic features, may benefit from referral to a medical geneticist. Although guidelines for genetic testing in children with ASD are evolving rapidly, those children with ASD and seizures/epilepsy would be expected to have a higher yield of genetic testing when compared to children with ASD alone (Ezugha et al. 2010; Shen et al. 2010)

Regression and evaluation In children with ASD and regression, an overnight EEG may be considered if the regression is active or ongoing, occurs after the typical time of regression which is between 1 and 2 years of age, or if regression is multiple/recurrent. The EEG is done to rule out electrical status epilepticus of sleep (ESES; Tuchman R. 2009). One condition associated with severe language regression and seizures, Landau-Kleffner Syndrome, should be considered if the regression is late (after 3 years of age) and primarily involves loss of language rather than loss of social skills. Children with this clinical pattern benefit from further evaluation by pediatric neurologist.

Management of Seizures in Children with ASD

First time seizures Current guidelines suggest that typically developing children with a first time seizure should not be treated unless the seizure was particularly prolonged or if the underlying neurologic exam is abnormal, as the risk of a subsequent seizure is only 50 % (Haut and Shinnar 2008). Children with a neurodevelopmental disability such as cerebral palsy have a higher risk of recurrence (Ramos-Lizanna et al.

2009). The recurrence rate of seizures in children with ASD is not known, but, as autism is a neurologically based disorder, children with autism are probably more likely than typically developing children to have a recurrence. Treatment after a single event will need to be decided with the family on an individual basis taking into account clinical features such as length of the seizure, family history of seizures, family concerns about recurrence, and the concurrent use of an antiepileptic medication for seizure prevention and behavioral intervention.

Treating EEG abnormalities There is no consensus regarding treatment of a child with ASD who has an EEG showing epileptiform activity but who is not having clinical seizures. Because some antiepileptic drugs, such as valproic acid, are also used to treat mood disorders, some families/providers may wish to try antiepileptic drugs empirically, especially if the child has mood instability (Hollander et al. 2001). Because this involves an off-label use of medication and is not standard of care, this will need to be decided on an individual basis. More research to inform the management of children with ASD with epileptiform abnormalities of the EEG but who are not having clinical seizures, is urgently needed.

General seizure management considerations Families of children who have had a seizure need education whether or not they are started on medication. Important points include:

1. Children with seizures are more likely to have one if they are tired or ill and parents and caregivers should be more vigilant during these times.
2. While it is not necessary to avoid flashing lights in all children with seizures, they may cause seizures in some (*approximately 9%, this becomes less common with age*). The frequency of flashing that is most likely to cause seizures varies from person to person but is generally between 15 and 18 Hz (Hughes 2008).
3. Children with seizures should be carefully supervised near water (bath tubs, swimming pools, hot tubs), hot water heaters, campfires, saunas, and cooking.
4. Seizures do not cause individuals to swallow their tongues. Caregivers should not try to place anything in the child's mouth but should lay them on the floor on their side.
5. All caregivers (teachers, etc.) should be aware of seizure precautions and management.
6. Most seizures are likely to stop before 5–10 min (Shinnar et al. 2001a); if they do not stop or the child appears to be having difficulty in breathing, emergency services should be called.
7. Families should consider emergency bracelets, necklaces, or other ways of imparting emergency information.
8. If a child has prolonged seizures, a prescription for a rescue medication may be helpful. Rescue medications include nasal midazolam and rectal valium (Diastat).
9. Families should be referred to reliable sources of information for seizures; examples are the Epilepsy Foundation website (www.epilepsyfoundation.org) and the seizure module of the Medical Home Portal (www.medicalhomeportal.org) contains a sample "seizure action plan" that can help providers and families develop shared treatment plans.

The use of antiepileptic medications in children with ASD Children with more than one seizure should generally be started on antiepileptic medication. If seizures stop with medication, treatment is continued for 2 years and then gradually tapered. The choice of which medication to use in children with ASD is more complicated than in a typically developing child as children with ASD will often have associated conditions, including attention problems, anxiety, and sleep problems. These associated conditions need to be considered when choosing medications (Pellock 2004). The choice of the specific medication should weigh the risks of specific side effects with the characteristics of the individual being treated (Azar and Abou-Khalil 2008). Ideally, a medication for seizures will be helpful for both the seizures and the associated condition. For instance, in an open trial of valproic acid in individuals with autism and seizures, impulsivity and aggression improved as well as seizures (Hollander et al. 2001). However, in a survey regarding the perceived effectiveness of medications in individuals with epilepsy and ASD, families responded that although the antiepileptic medications helped treat seizures they worsened other factors such as sleep, behavior, and communication (Frye et al. 2011). For these reasons, in most circumstances the child's primary care physician should strongly consider obtaining a consultation from a pediatric neurologist to look at this issue carefully. It is possible that several medication trials will be necessary to achieve the optimum balance between seizure control and avoiding behavior, attention, or sleep problems.

Extended release preparations may have fewer side effects than immediate release preparations as blood levels stay more constant. However, extended release preparations may be more expensive as they are often newer and are not considered first line medications by insurance companies. A letter of medical necessity delineating why the extended release preparation is necessary may be helpful.

The form of medication, whether it is liquid, sprinkle capsules, tablets, or capsules must be considered as many children with ASD may refuse to take medications in a certain form (Williams et al. 2000). The active ingredient and additional substances in the tablet or capsule need to be considered if the child is on a special diet. In an individual who has a difficult time with blood draws, medications requiring regular blood monitoring should be avoided when possible.

The effects of antiepileptic medications on appetite should also be considered. Topiramate, which may decrease appetite, might not be the best first choice for children who are very picky eaters. Valproic acid may lead to weight gain.

Children who have difficulty sleeping should not, as the first choice, be put on medications which may keep them awake. For instance, topiramate causes wakefulness in some individuals whereas other medications for seizures may be helpful for sleep induction.

Some of the antiepileptic medications are more helpful in children with generalized epilepsy (levetiracetam, lamotrigine, valproic acid) whereas others are used in those with partial epilepsy (oxcarbazepine; Azar and Abou-Khalil 2008). Many of the newer medications are more expensive than older medications but do not require blood level monitoring so they may be cheaper and easier in the long run. The newer medications are also less likely to have significant side effects and/or drug interactions. All of the medications used for seizures may cause sleepiness, difficulty with retaining information, irritability, and other changes. Most of these will diminish after the first few days of use but may be severe enough to necessitate a trial with a different medication. Medication should be started at the lowest recommended dosage and titrated up with incremental changes to enhance effectiveness and tolerability. Increases in dose can usually be done every few days or weekly. An exception is lamotrigine which requires a longer interval (2 weeks) between dose increases. Written and understandable instructions on how to titrate the dose should be given to the family. As there is no perfect medication, families should be encouraged to stay with one medication for at least a few weeks before coming to a decision about the medication.

Patients and families should be instructed to call if a rash develops after starting a medication. If a rash occurs, the patient should be seen emergently and, if it is probable that it is a drug rash, the medication should be stopped. If the patient has frequent seizures, this will need to be done as an inpatient. The rash needs to be gone before starting a second medication (Prais et al. 2006).

Idiosyncratic drug reactions, most likely occur during the first few weeks of therapy, are rare; potentially fatal reactions occur unpredictably and do not necessarily correlate with the dose or blood level. When starting a new medication, families should be advised to watch for temperatures over 40 °C, protracted vomiting, lethargy, skin exfoliation, mucosal, palm, or sole lesions, edema, skin pain, palpable purpura, protracted bleeding from minor cuts, lymph node enlargement, or asthmatic symptoms. Prescribing information should be consulted for side effects of specific medications.

If the initial medication is initially ineffective for control of seizures, the dose may be increased until satisfactory seizure control occurs or until side effects are persistent and intolerable. If the medication fails, a second medication will be titrated up as the first is tapered off. This needs to be done extremely slowly if the two medications are valproic acid and lamotrigine as a sometimes fatal rash called Stevens Johnson syndrome may develop. Some children with ASD and seizures may require several medications to keep their seizures under adequate control, but the initial goal is one medication. It is estimated that 20–30 % of children with epilepsy are resistant to treatment with medications.

Other treatments of epilepsy in children with ASD Alternative treatments for epilepsy include the ketogenic diet and epilepsy surgery. These alternatives are usually considered when medication treatment fails, although sooner rather than later is preferable. Although the ketogenic diet is "just a diet," it causes profound changes in body metabolism and is not necessarily safer than medications. It generally requires an admission to the hospital to initiate and is difficult and expensive. A modified Atkins diet and a low glycemic index diet may also be helpful and are easier to initiate and follow (Kelley and Hartman 2011). Epilepsy surgery is of two basic types, removing or disconnecting a specific brain area thought to be causing the seizures, or implanting a vagal nerve stimulator.

Children with an ASD and difficult to control epilepsy are best managed at a comprehensive epilepsy center where comprehensive evaluation and alternative treatment such as the ketogenic diet and epilepsy surgery are available and where trials of new treatments are underway.

Sleep Problems in Children with ASD

Introduction

Insomnia, defined as difficulty initiating or maintaining sleep, is commonly reported by parents of children with ASD. Specifically, children with ASD are more likely to exhibit prolonged sleep latency (time to fall asleep), bedtime resistance, decreased sleep efficiency (decreased time asleep in relation to time in bed), decreased sleep duration and continuity, and increased awakenings (Couturier et al. 2005; Krakowiak et al. 2008; Richdale 1999). Overall, prolonged sleep latency is more prevalent, compared to sleep maintenance insomnia (difficulty staying asleep; Krakowiak et al. 2008; Richdale 1999; Gail Williams et al. 2004), although children with ASD frequently experience aspects of both.

In this section, we will review the principles that help children with ASD make the transition to sleep most effectively: predictable bedtime routines and good "sleep hygiene." We will begin by presenting the epidemiology of sleep problems in children with ASD and how they may adversely affect children and families. We will then review the specific steps in evaluating children with ASD who present with sleep problems, emphasizing the key elements of history taking and when further studies are needed. Once the diagnosis is made we will conclude with treatment strategies for specific sleep disorders in children with ASD. Because of the benefits to both the child and family, successful treatment of a sleep problem in a child with ASD can be an extremely rewarding endeavor.

The Etiology of Sleep Problems in Children with ASD

Sleep problems in children with ASD have many causes that include neurobiological factors such as aberrations in neurotransmitter systems that promote sleep and establish a regular sleep-wake cycle (e.g., melatonin) and medical disorders that disrupt sleep continuity (e.g., neurological conditions such as epilepsy, gastrointestinal disorders such as reflux, psychiatric conditions, and primary sleep disorders such as sleep apnea). Additionally, the core behavioral features associated with ASD may predispose children with ASD to behaviorally based sleep disorders. (Table 25.4)

Table 25.4 Causes of sleep disturbance in autism

Poor sleep habits
Hypersensitivity to environmental stimuli
Hyperarousal/difficulty with self regulation
Medical concerns that may cause pain, discomfort, or sleep disruption (eg, constipation, gastroesophageal reflux, eczema, tooth pain, coughing/asthma)
Repetitive thoughts or behaviors that interfere with settling
Inability to benefit from communication/social cues regarding sleep
Co-occurring psychiatric conditions (eg, anxiety, depression)
Psychotropic medications
Coexisting epilepsy
Obstructive sleep apnea
Restless Legs Syndrome/periodic limb movements of sleep
Circadian rhythm abnormalities

Epidemiology/Prevalence of Sleep Problems in Children with ASD

The prevalence of sleep problems in children with ASD is approximately 50–80% compared to 9–50% in children with typical development (Couturier et al. 2005; Krakowiak et al. 2008; Richdale and Schreck 2009; Souders et al. 2009). Children with ASDs are also reported to have sleep problems more frequently than children with other developmental disabilities (Schreck and Mulick 2000; Wiggs and Stores 1996). Unlike children with other developmental disorders, more impaired cognitive function and younger age do not always predict severity of sleep problems in children with ASD as children with high functioning autism and Asperger syndrome have a high rate of sleep disturbance as well (Krakowiak et al. 2008; Malow et al. 2006a; Patzold et al. 1998; Richdale 1999).

Effects of Sleep Problems on Daytime Function in Children with ASD and their Families

Sleep disturbances may contribute to increased stress in families of children with ASD and developmental disabilities. Sleep problems in children with ASD are associated with more daily stress and more intense "hassles" by parent report (Honomichl et al. 2002b). Sleep problems in children with developmental disorders have also been associated with parental sleep disruption (Quine 1991). Sleep problems may worsen daytime behavior in individuals with developmental disabilities (Didde and Sigafoos 2001). Behavioral issues such as inattention and hyperactivity may be worsened by the presence of sleep disorders such as obstructive sleep apnea (Chervin and Archbold 2001; Chervin et al. 2002). In ASD, short sleep duration is associated with higher rates of stereotypic behavior, higher overall autism severity scores and social skills' deficits (Gabriels et al. 2005; Schreck et al. 2004a), and higher levels of parental concerns for many behavioral issues (Goldman et al. 2011). It is critical to identify and address sleep problems in children with ASD, due to the impact on health and quality of life in both the children and their parents.

Specific Sleep Conditions in Children with ASD

Behavioral Insomnia of Childhood This sleep disorder manifests as difficulty falling and/or staying asleep and is related to an identified behavior in the child or caregiver. It occurs in 10–30% of typically developing toddlers and preschoolers (Meltzer and Mindell 2006) and may occur more frequently in toddlers, preschoolers, and older children with ASD. This disorder has two subtypes:

- **Limit-setting type:** This subtype manifests as the child either stalling to go to bed (e.g., frequent requests to use the bathroom) or refusing to stay in bed (e.g., making "curtain calls" requesting another story). Upon setting appropriate limits, most typically developing toddlers and preschoolers will "outgrow" this condition by school age (Meltzer and Mindell 2006). Children with ASD, however, may have difficulty with emotional regulation, perseverative thoughts or behaviors, or transitions that interfere with the establishment of bedtime routines; *going to sleep is the ultimate transition*. Children with ASD also may not understand the expectations of parents related to going to sleep. In response to bedtime difficulties parents may decide not to set any limits, allowing children to fall asleep whenever they finally become tired or they may set inconsistent limits that provoke intense temper tantrums from the child.

- **Sleep-onset association type:** Sleep associations are certain conditions that must be met to help a child fall asleep and without those conditions, sleep onset may be prolonged and/or the child may have difficulty falling back to sleep after a night waking. Most children with typical development can learn to "self-soothe" (e.g., cuddle with a stuffed animal) in order to independently initiate or fall back asleep. This sleep disorder develops when a child becomes dependent on a negative sleep association (e.g., a caregiver that holds, rocks, or feeds the child or provides a car ride or television program) to fall asleep at bedtime or after a night waking (Bhargava 2011). Sleep-onset association type occurs primarily in typically developing infants and toddlers but may persist later into childhood in those with ASD.

Sleep-Related Breathing Disorders

- Obstructive Sleep Apnea (OSA): Sleep disordered breathing encompasses disorders related to airway obstruction and includes OSA. While not necessarily more common in children with autism, sleep disordered breathing is common in the general pediatric population, adversely affects daytime behavior, contributes to daytime sleepiness or attention-deficit/hyperactivity symptoms, and improves after adenotonsillectomy (Chervin et al. 2002; Goldstein et al. 2002; Gottlieb et al. 2003). Hypotonia, which can be seen in children with ASD and other developmental disorders, can also contribute to OSA. In one report, treatment of OSA in a child with ASD improved daytime behaviors (Malow et al. 2006b).

Parasomnias Parasomnias are undesirable physical events that occur during entry into sleep, within sleep, or during arousal from sleep. Several are common in children with ASD:

- Non-rapid eye movement (REM) arousal disorders: The non-REM arousal disorders, such as night terrors, sleep walking, and confusional arousals, usually occur in the first half of the night and during deep sleep. It is unclear whether there is a higher rate of these disorders in individuals with ASD than in comparison groups (Honomichl et al. 2002a; Patzold et al. 1998; Richdale and Prior 1995; Schreck and Mulick 2000).
- REM-associated sleep abnormalities: During REM sleep, muscles are typically "paralyzed" so that an individual cannot "act out their dreams." REM sleep behavior disorder (RBD) occurs when this atonia does not occur. RBD has been reported in one case series of children with ASD who were studied with polysomnography (PSG; Thirumalai et al. 2002). A larger PSG study that excluded children on psychotropic medication did not document RBD in children with ASD (Malow et al. 2006a). RBD can occur in association with medications that affect REM sleep, such as the selective serotonin reuptake inhibitors (Mahowald and Schenck 2005).

Sleep-Related Movement Disorders

- Rhythmic Movement Disorder: Rhythmic movement disorder is characterized by repetitive motion of the head (including head banging), trunk, or limbs, usually during the transition from wakefulness to sleep (Hoban 2003). It may also arise during sustained sleep. Although the condition most often affects infants and toddlers with typical development in a transient and self-limited fashion, it may be more persistent and increased in intensity in children with autism and other developmental disabilities. Padding the sleeping environment can be helpful.

- Restless Legs Syndrome/Periodic Limb Movements in Sleep/Periodic Limb Movement Disorder (RLS/PLMS/PLMD): Restless legs syndrome (RLS) is a sensorimotor disorder which involves an urge to move the legs and an uncomfortable sensation that typically occurs at bedtime, is worse at rest, and is relieved by movement. Periodic limb movements in sleep (PLMS) are defined by repetitive stereotypic movements of the limbs during sleep. Diagnosing RLS is difficult even in typically developing children under age 5, due to an inability to fully communicate symptoms (Simakajornboon 2009).

Melatonin and Circadian Rhythm Disturbances Humans have an internal clock which is called a circadian rhythm. This rhythm is not exactly 24 hrs and so must be entrained by other stimuli, the most important of which is light. A decrease in light is associated with secretion of melatonin, a sleep promoting substance which is released by the pineal gland (Gooley and Saper 2005). It is synthesized from serotonin (Lin-Dyken and Dyken 2002). There are reports from small studies of abnormal platelet serotonin levels in children with autism (Rapin and Katzmann 1998) and low levels of melatonin secretion in individuals with ASD (Kulman et al. 2000; Melke et al. 2008; Nir et al. 1995; Tordjman et al. 2005), and in one study, the level of the major metabolite of melatonin (6-sulfatoxymelatonin) was directly related to the level of deep sleep in children with ASD (Leu et al. 2011). There have also been conflicting studies but most have found differences in the genes that regulate the melatonin pathway in individuals with ASD (Cai et al. 2008; Jonsson et al. 2010; Melke et al. 2008; Toma et al. 2007). It is expected that a better understanding of these genetic variations and their impact on sleep will lead to better treatments in the future.

Evaluation of Sleep Problems in Children with ASD

Sleep problems in children with ASD may be overlooked because daytime behavioral issues often take precedence so it is always important to screen for sleep issues even if the parents do not bring it up. A comprehensive sleep history and if necessary, further work up and referral should be completed in children with ASD as with any child who has sleep issues. An insomnia algorithm has been developed by the Autism Treatment Network (Malow, 2012).

The comprehensive sleep history The sleep history obtained by the provider should include information about bedtime problems, excessive daytime sleepiness, awakenings during the night, regularity and duration of sleep, and snoring (Bhargava 2011). In general, children should be able to fall asleep within 30 min of bedtime, thus a longer amount of time would indicate a sleep problem. If the child takes an extended time to fall asleep, asking about the bedtime routine may help in determining if there is a behavioral cause that can be modified. For example, screen time (computer, television, or video games) shortly before bedtime may adversely affect a child's ability to fall asleep. Likewise, a child who is simply not tired or seems unable to find a comfortable spot in bed might be important clues to a primary sleep disorder, such as RLS.

Average sleep times for children with typical development have been published elsewhere (Meltzer and Mindell 2006). When asking about the presence and duration of night waking, associated behaviors, and need for intervention, it is very important to look for potential reinforcers of night waking such as food provided by caregivers.

Questions about the sleep environment may help identify potentially modifiable factors that affect sleep. For example, some children may be oversensitive to environmental stimuli such as scratchy diapers, uncomfortable pajamas or an overly warm, loud, or lit bedroom. Identifying these issues may be particularly challenging in children with ASD who often have difficulty communicating pain or discomfort.

To complement the comprehensive sleep history, sleep and behavioral questionnaires, and sleep diaries may further aid the clinician to identify a specific sleep disorder. The Children's Sleep Habits Questionnaire (Owens et al. 2000) assesses sleep-related breathing disorders, sleep anxiety, bedtime resistance, and daytime sleepiness. The Family Inventory of Sleep Habits (FISH) is a measure of sleep habits, including bedtime routine; sleep environment, and parental interactions (Reed et al. 2009). A behavioral rating scale such as the Child Behavior Checklist (Achenbach and Rescorla 2000) can screen for psychiatric and behavioral issues which may impact sleep. For example, mood disorders are seen more commonly in children with ASD and may significantly impact sleep (Leyfer et al. 2006). A sleep diary can be helpful to assess sleep latency (time to fall asleep), total sleep time, night waking, and response to treatment. (http://kidzzzsleep.org/professionals/clinical-tools/)

Further testing for primary sleep disorders If the comprehensive sleep history reveals the presence of symptoms or risk factors for treatable primary sleep disorders such as sleep-related breathing disorders, RLS, or seizures, further testing should be considered. While blood tests are rarely required, if the comprehensive sleep history reveals restless sleep, iron studies should be considered. Both RLS and PLMD are associated with iron deficiency (Dosman et al. 2007; Simakajornboon et al. 2009) and may improve with iron treatment (Dosman et al. 2007). There are several small studies that reported a high rate of iron deficiency in children with ASD (Latif et al. 2002) and another small study reported low ferritin, a marker of iron deficiency, in children with ASD who also had restless sleep (Dosman et al. 2007).

PSG, commonly referred to as a “sleep study,” is the “gold standard” for measuring sleep in children, including the detection of sleep apnea, seizures, parasomnias, and periodic limb movements. Because it involves the child staying overnight in a sleep laboratory attached to monitoring equipment, it does have limitations in terms of child tolerance, timely availability, and expense. However it is important to be aware that desensitization therapy prior to PSG can work well for many children with ASD. Actigraphy, a methodology that measures sleep and wake patterns based on limb movement, represents an alternative to PSG for documenting sleep patterns in children with autism. It is especially helpful in insomnia. Actigraphy is performed in the child’s home environment, and may be especially helpful in those with tactile sensitivities or anxiety in novel environments such as a hospital sleep laboratory. The clinician should become aware of what resources (PSG, home actigraphy or specialized sleep medicine clinics) are available in the community to assist in the evaluation of children with sleep problems.

Further Work Up for Co-occurring Conditions That May Cause Sleep Problems

As mentioned earlier, insomnia may result from a coexisting medical condition. Based on the history, further testing and treatment for co-occurring disorders that cause pain or discomfort such as gastroesophageal reflux, constipation, dental issues, or eczema may be indicated. Coexisting epilepsy or its treatment may also disrupt sleep and referral for PSG with EEG, if there is a concern for sleep-related seizures, may be appropriate (Malow 2004). Likewise, co-occurring psychiatric conditions such as attention deficit hyperactivity disorder (ADHD), anxiety, or depression can interfere with sleep, as can the psychotropic medications often used to treat these conditions. Depression may be manifested by early morning waking, and bipolar disorder by decreased need for sleep. Anxiety, which is particularly common in children with Asperger syndrome, may lead to difficulty falling asleep alone, and obsessive-compulsive disorder may result in prolonged sleep latency due to excessive bedtime rituals. If any of these psychiatric conditions are suspected, referral to a mental health specialist may be indicated.

Treatment of Sleep Problems in Children with ASD

Sorting out the etiology of insomnia in children with ASD can be challenging, because multiple issues may be contributing to the sleep problems simultaneously. Treatment of medical or psychiatric conditions that affect sleep (such as constipation, gastroesophageal reflux, or epilepsy) is essential and has been covered earlier in this chapter. If a primary sleep disorder is identified, the treatment is based on the specific condition diagnosed. For example, a clinical guideline for the treatment for OSA has established adenotonsillectomy as the first line therapy and continuous positive airway pressure as an option for children who are not surgical candidates or do not respond to surgery (Chapman et al. 2012). If RLS and iron deficiency are diagnosed, iron supplementation may be indicated (Dosman et al. 2007). If REM abnormalities are associated with the use of SSRIs, the clinician may consider a medication change. All of these conditions may require the primary care physician to coordinate with other specialists and the family to design and implement a treatment strategy.

The importance of sleep hygiene Regardless of the cause of the sleep problem, the treatment of insomnia in children with ASD should include education for caregivers that establishes good "sleep hygiene": habits that support healthy sleep. Even though parents face many stressors and multiple priorities, clinicians should stress the importance of a healthy sleep environment, and certain daytime and evening habits as the cornerstone in the treatment of insomnia in children with ASD (Reed et al. 2009). The *sleep environment* should be cool with minimal light and sound (for children hypersensitive to noise, a continual noise machine may be helpful to drown out environmental sounds and for children who are hypersensitive to touch, texture of bedding and pajamas should be explored, also deep pressure might work better than light touch, a study of use of a weighted blanket is underway in England). Healthy *daytime habits* include adequate exercise, exposure to light, and limiting caffeine and naps. Healthy *evening habits* including decreasing excess stimulation (especially from electronics), decreasing exposure to light, and having a predictable bedtime routine that includes a series of tasks or activities that occur at the same time and place every night (Jan et al. 2008).

Behavioral Treatments for Sleep Problems in Children with ASD

In addition to sleep hygiene interventions, various behavioral treatments are effective for the behavioral insomnias (limit setting or sleep-onset association) in children with typical development (Morgenthaler et al. 2006). One technique, known as graduated extinction, involves putting the child to bed and leaving the room while he or she is still awake. The parent then checks on the child in progressively increasing intervals of time until sleep is achieved. It was previously believed that these treatments might not be effective in children with developmental disabilities but newer studies are beginning to indicate the opposite. Behavioral treatment of sleep problems in children with intellectual disabilities reduces parental stress, increases parents' satisfaction with their own sleep and their child's sleep, and heightens their sense of control and ability to cope with their child's sleep (Wiggs and Stores 2004). Several interventions for parents of children with ASD that included parental sleep education and behavioral strategies demonstrated subjective and objective (actigraphy) improvements in insomnia as well as aspects of daytime behavior and parental stress (Moon et al. 2010; Reed et al. 2009). Children with ASD typically respond well to visual cues and routines once established. A visual schedule can be quite helpful for children with ASD (Fig. 25.1) and a story about another child going to sleep may help as well (Reynolds and Malow 2011). It is becoming clear that established behavioral sleep interventions for typically developing children can be tailored to meet the needs of a child with ASD; a frequently recommended book provides guidance for parents on how to implement these strategies (Durand 1998).

Melatonin and Other Pharmacologic Treatments

Whether the sleep problem primarily involves sleep initiation or a circadian phase shift, a combination of sleep hygiene and melatonin may

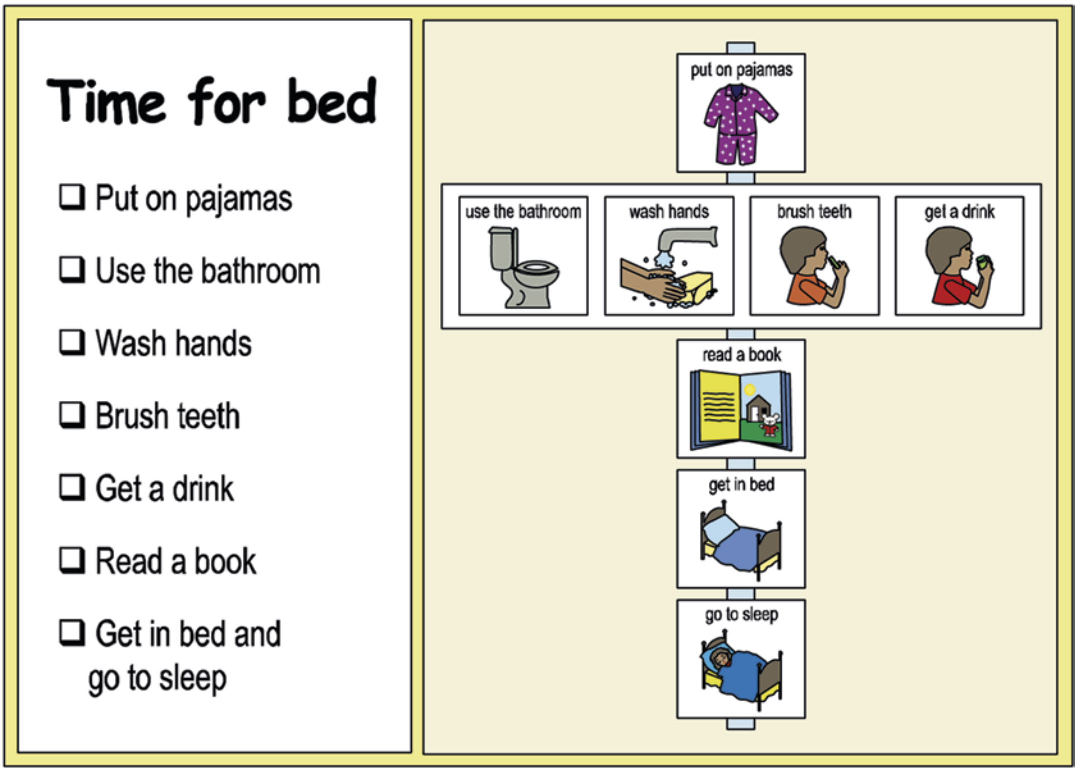

Fig. 25.1 Picture schedule. Picture schedules can be particularly helpful for children with ASD who respond better to visual stimuli than to auditory stimuli

be useful before considering other medications. Synthetic melatonin is available as a dietary supplement. While studies have not been shown to support the use of melatonin to treat sleep disorders in children with typical development, a meta-analysis, which included studies of children with ASD (Braam et al. 2009), found that melatonin appears to be safe and effective in the short term in individuals with an intellectual disability. There have also been some studies that evaluated the use of melatonin specifically in children with ASD. A retrospective open label study of 107 children with ASD that included long-term follow-up (Andersen et al. 2008) and several small open label or randomized trials found improvement in sleep latency with melatonin and minimal adverse effects (Garstang and Wallis 2006; Giannotti et al. 2006; Paavonen et al. 2003; Wright et al. 2010). While there is the need for larger placebo-controlled trials, there appears to be enough evidence to consider use of melatonin in children with ASD who have significant issues with sleep onset latency.

When behavioral therapies and melatonin are ineffective, pharmacologic treatment can be considered (Owens and Moturi 2009). While many different medications have been used in clinical practice, including clonidine, trazodone and other sedating antidepressants, and atypical antipsychotics (Owens et al. 2010), there are very little data to guide the use of psychotropic medications in children with ASD. A helpful principle for prescribing sleep medications in children with coexisting neurologic or psychiatric disorders is to consider the overlapping neurological systems that are affected. Wherever possible, prescribe a medication for the coexisting condition that also assists with sleep, while avoiding those that cause insomnia. In children with coexisting epilepsy or bipolar disorder, for example, mood stabilizers with sedating properties such as atypical antipsychotics or anticonvulsants may be a reasonable choice. The antiepileptic regimen can be adjusted to administer a bedtime dose of medication that provides sedation and promotes sleep. The dosages of these medications can be adjusted to give the higher dose at bedtime.

Conclusions and Future Directions

In this chapter, we have reviewed several commonly encountered medical conditions in children with ASD: gastrointestinal disorders, sleep disorders, and seizures/epilepsy. All of these conditions have a significant impact on daytime functioning and parental stress. Effective treatment strategies are dependent on understanding the underlying etiologies of these conditions. A careful history that accounts for the non-traditional manifestations of these conditions in children with ASD is extremely important as is interdisciplinary collaboration to develop treatment plans. Successful management depends on providers who partner with families and offer ongoing care within a medical home for children with ASD.

The current management of associated medical conditions in children with ASD is largely based on small-scale studies and expert opinion. In the future, practitioners will benefit from larger-scale studies that better inform decisions about treatment options. The Autism Treatment Network (ATN) was established in 2005 as the first network of ASD clinical and research centers. The ATN is comprised of 17 sites across North America that engage in clinical care and shared research to develop best practices and standards of care in the treatment of children with ASD. The network is involved in ongoing research and currently developing clinical guidelines for the evaluation and treatment of constipation, diarrhea, insomnia, and seizures. This work from the ATN and others will expand the knowledge about associated medical conditions and help practitioners to better serve children with ASD in the years to come.

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Behavioral Disorders in Young Children with Autism Spectrum Disorder

26

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Keywords

Challenging behavior · Functional assessment · Behavior intervention plan

Autism Spectrum Disorder (ASD) is a term used to describe a broad class of neurodevelopmental disorders associated with impairments in communication, reciprocal social interactions, and patterns of restricted or repetitive behaviors and interests (Johnson et al. 2010; National Institute of Child Health & Human Development [NICHD] 2011). ASD encompasses a range of disorders that generally include the DSM-IV-TR Pervasive Developmental Disorders: Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (American Psychiatric Association [APA] 2000). Prevalence estimates for ASDs range from 3 to 7 in 1000 (Fombonne 2009; Rutter 2005), highlighting ASDs as a serious public health concern. As a result there is growing emphasis on early identification of and intervention with ASDs. The importance of early detection and diagnosis is evident, as interventions for ASDs generally are more effective when implemented as early as possible in the course of the disorder (Matson et al. 2012; Peters-Scheffer et al. 2011). The behavioral characteristics of ASDs often are readily observed in children of very young ages. Developmental concerns associated with ASDs are seen by parents and health care professionals as early as 18—24 months of age (Osterling et al. 2002; Young et al. 2003), with diagnosis of an ASD often made between the ages of 2 and 3 years (Dixon et al. 2011).

One important aspect of early intervention for persons with ASDs is early identification and treatment of challenging behaviors, such as self-injurious behavior (SIB) or aggressive behaviors. Challenging behaviors are a significant problem for many persons with ASD, often persisting into adolescence and adulthood (Matson, Mahan et al. 2010). Furthermore, these behaviors are associated with adverse outcomes, such as increased risk of mental health disorders (Myrbakk and Tetzchner 2008), fewer social interactions with adults and peers (Matson, Neal et al. 2010), and impeded learning and development (Matson 2009).

While challenging behaviors are not a core feature of ASDs, individuals diagnosed with ASDs are at an increased risk of developing a challeng-

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ing behavior (Dawson et al. 1998; McClintock et al. 2003). In a sample of 182 children and adolescents with ASDs, Matson, Wilkens et al. (2009) found that 94.3% of participants exhibited at least one form of challenging behavior. The increased risk for challenging behaviors is evident even at very young ages, as children with ASDs are at greater risk of developing challenging behaviors than typically developing peers and peers with other developmental disabilities (Gadow et al. 2004; Hartley et al. 2008). Hattier et al. (2011) evaluated 633 children with ASDs between the ages 17–37 months, and found 77.4% of caregivers endorsed at least one challenging behavior for their child; endorsement of 15 individual challenging behaviors ranged from 10.4 to 41.7%.

Challenging behaviors have received an abundance of attention in the literature, but much of this has focused on older children, adolescents, and adults. By comparison, there are fewer empirical studies of challenging behaviors for infants and young children diagnosed with ASD (Matson and Nebel-Schwalm 2007). Given the emphasis on early identification and intervention for ASDs, there is a need to better describe and understand the challenging behaviors of infants and young children diagnosed with ASDs. While persons with ASDs exhibit the full range of difficult and challenging behaviors as their typically developing peers, the focus of this chapter will be on the challenging behaviors that are more typically associated with ASDs. As such, the purposes of this chapter are to 1) describe the most significant challenging behaviors observed in young children diagnosed with ASDs, including stereotypies, self-injury, aggression, and destructive/disruptive behaviors, 2) describe behavioral and psychiatric assessment of these challenging behaviors, and 3) describe behavioral and pharmacological interventions for these challenging behaviors.

Challenging Behaviors

Stereotyped Movements and Ritualistic Behaviors One core diagnostic feature of most ASDs is the presence of repetitive behaviors or interests (APA 2000). Most often referred to as stereotyped behaviors, or stereotypies, this class of behaviors also includes ritualistic, obsessive-compulsive, and perseverative behaviors (Bodfish et al. 2000; Ringdahl 2011). While the distinctions among these terms are not always clear, collectively these behaviors are characterized by repetitive, rhythmic, and seemingly purposeless behaviors (Goldman et al. 2009; Turner 1999). Typical stereotypies include body rocking, hand and arm flapping, mouthing objects, finger tapping, clapping, arranging objects, spinning or shaking objects, and inappropriate vocalizations (Cunningham and Schreibman 2008; Goldman et al. 2009). Body rocking, finger flicking with and without objects, and hand flapping are more prevalent in persons with ASDs, and perhaps associated with the disorder (Abelson 1983; Berkson and Tupa 2000; Murphy et al. 2009).

Stereotypies are observed in both typically developing individuals and individuals with intellectual and developmental disabilities (IDD) as young as 1 or 2 years of age (MacDonald et al. 2007; Matson, Dempsey et al. 2009; Singer 2009). Under most circumstances, these behaviors are hypothesized to be a typical, but transient aspect of motor and neurological development, and usually remit by 5 years of age (Foster 1998; Singer 2009; Thelen 1979, 1996; Tröster 1994). For children with IDDs, especially ASDs, the onset of stereotypies tends to be later than that of typically developing children, with the behaviors often persisting well beyond childhood (Lord 1995; Matson, Mahan et al. 2010; Symons et al. 2005). MacDonald et al. (2007) examined stereotypies of young children diagnosed with ASDs and typically developing peers, and found the occurrence of stereotypies at age two was only slightly higher for the ASD group, but substantially higher at ages 3 and 4 years. Matson, Mahan et al. (2010) examined challenging behaviors, including stereotypies, in a group of children ages 3–14 years with ASDs and found no differences across the age groups in regards to the occurrence of stereotypy, suggesting these behaviors likely are chronic.

Prevalence estimates vary, but suggest that up to 72% of individuals diagnosed with ASDs exhibit some form of stereotypy (Berkson 1983;

Bodfish et al. 2000; Goldman et al. 2009; Matson, Dempsey et al. 2009; Matson and Rivet 2008). When compared to typically developing peers and other individuals diagnosed with IDDs, there is an increased occurrence of stereotypies in children with ASDs (Bodfish et al. 2000; Hattier et al. 2011; Kozlowski and Matson 2012; Matson, Dempsey et al. 2009; Murphy et al. 2009). Furthermore, stereotypies are the most frequently reported challenging behavior for children with ASDs (Jang et al. 2011; Matson, Wilkins et al. 2009).

Stereotypies do not always result in severe problems for the individual, nor require intervention. For example, Hattier et al. (2011) found that only 46.1 % of children ages 17–37 months were rated by caregivers as exhibiting a problematic form of stereotypy. As a result, stereotypies often are overlooked and receive less attention than other challenging behaviors (Matson et al. 1996). However, in many cases stereotypy can interfere with skill acquisition (Koegel and Covert 1972; Matson et al. 1997), can be associated with other more severe challenging behaviors, such as self-injury (Jones 1991), and can result in negative social consequences for the individual, such as social avoidance and lower levels of adult and peer interaction (Jones 1991; Matson, Wilkins et al. 2009; Matson, Neal et al. 2010; Matson and Rivet 2008). Consequently, there has been increasing investigation into interventions for stereotypies (Ahrens et al. 2011; DiGennaro Reed et al. 2012; Ringdahl 2011). While stereotypies traditionally have been considered “purposeless,” there is considerable evidence that these behaviors are maintained in whole or in part by automatic reinforcement, such as sensory stimulation (Dawson et al. 1998; DiGennaro Reed et al. 2012; Rapp 2006). Although stereotypies may emerge due to internal or sensory factors, the behaviors can acquire social, operant functions over time, such as escape from nonpreferred tasks (Durand and Carr 1987), and access to attention from others or preferred items or activities (Ahearn et al. 2003; Goh et al. 1995). Additionally, other severe challenging behaviors have been demonstrated to occur in response to the blocking or interruption of stereotypies and rituals (Hanley et al. 2000; Hausman et al. 2009; Murphy et al. 2000).

Self-injurious Behavior Self-injurious behavior, or SIB, is defined as any behavior directed towards oneself that results in tissue damage or injury to the person (Tate and Baroff 1966). SIB presents in a variety of forms, but the most commonly observed topographies include head banging, head hitting, body hitting, self-scratching, self-biting, eye poking, and hair pulling (Schroeder et al. 1980). A common challenging behavior for persons with IDDs, SIB is not confined solely to persons with IDDs; it is often observed in typically developing children, but usually is transient, resolving by 5 years of age (Bachman 1972; de Lissovoy 1961; Romanczyk et al. 1982). For persons with IDDs, SIB is more chronic and pervasive with prevalence estimates ranging from 4.9 to 17 % (Cooper et al. 2009; Rojahn 1994).

Individuals diagnosed with ASDs seem to be at greater risk of developing chronic or persistent SIB (Dominick et al. 2007) with prevalence estimates as high as 69 % (Baghdadli et al. 2003; Bodfish et al. 2000; McTiernan et al. 2011). The occurrence of SIB in young children with ASDs is similarly high especially in comparison to typically developing peers and peers diagnosed with other IDDs (Baghdadli et al. 2003; Hattier et al. 2011; McTiernan et al. 2011). Recent research has demonstrated that SIB is readily observed and likely has its roots in early childhood (Berkson and Tupa 2000; Hattier et al. 2011; Matson, Mahan et al. 2010; Schneider Bijam-Schulte et al. 1996), but may be overlooked due to the low intensity of the behavior, as well as the lack of resulting injury (Berkson and Tupa 2000; Berskson et al. 2001).

At first glance, the higher incidence of SIB in persons with ASDs may appear due to an apparent direct association between SIB and stereotypy. The DSM-IV-TR has aided in this association by categorizing self-injury as a specifier under Stereotypic Movement Disorder (APA 2000). Furthermore, some forms of SIB have been postulated to develop directly from stereotypies (Guess and Carr 1991; Richman and Lindauer 2005). With stereotypy being a core feature of ASDs, this would seem to explain the higher prevalence of SIB in persons with ASDs. However, while some forms of SIB may be associated with stereotypy, there is a significant body of evidence that demonstrates SIB to be maintained by social operant factors (Iwata, Dorsey et al. 1994; Iwata, Pace et al. 1994; O'Reilly et al. 2009; Vollmer, Sloman et al. 2009). Additionally, the incidence of SIB in ASDs is not significantly different from other IDDs, when intellectual disability is taken into account (Chadwick et al. 2000; Cooper et al. 2009). The evidence suggests that SIB is not significantly related to the core features of ASDs, but rather inversely correlated with intellectual ability (Griffin et al. 1986; McClintock et al. 2003; McTiernan et al. 2011). Therefore, the link of ASDs to SIB likely is indirect and solely a function of increased prevalence of intellectual disability in persons with ASDs (National Research Council 2001).

Aggressive Behaviors Aggressive behaviors generally are defined as inappropriate physical contact directed towards another person that may result in harm or injury, and include such topographies as hitting, kicking, biting, pinching, scratching, hair pulling, grabbing, and choking (Luiselli 2009). Aggressive behaviors constitute one of the most frequently occurring and impairing challenging behaviors for persons with ASD, and have significant adverse consequences for the individual, such as interference with learning and skill acquisition, increased likelihood of social isolation, more restrictive school and home placements, and risk of harm to self and others (Cohen et al. 2011; Horner et al. 2002; Luiselli 2009; Matson, Boisjoli et al. 2009; Matson et al. 2005). In a sample of 3,547 adults, Cohen et al. (2011) found the reported occurrence of aggressive behaviors ranged from 6 to 52% of subjects depending on the topography of aggression, including verbally aggressive behavior. Hattier et al. (2011) reported that between 69.5% of children ages 3 years and under with ASDs were endorsed by their parents as displaying at least one form of aggression. This provides further evidence that aggressive behaviors likely develop at a young age and persist in adolescence and adulthood (Matson, Mahan et al. 2010).

Aggressive behaviors are not a core feature of ASDs, but occur with enough frequency that their link to ASDs may be more intimate than previously believed. In most cases, the occurrence of aggression in children with ASDs is associated with typical antecedents and consequences, such as escape from nonpreferred academic tasks (McComas et al. 2000) or access to attention or preferred items and activities (Love et al. 2009). Aggression in some instances has been demonstrated to be maintained by automatic reinforcement (Luiselli 2009; Thompson et al. 1998). For example, Thompson et al. (1998) described a 7-year-old boy diagnosed with pervasive developmental disorder, whose aggressive chin pressing was maintained by tactile stimulation.

However, the higher incidence of aggression in persons with ASDs also may suggest an association with certain ASD core features, such as poor social and communication skills (Luiselli 2009), problems with transitions or changes to routines (Matson 2009; Sterling-Turner and Jordan 2007), or the occurrence of stereotyped and repetitive behaviors (Reese et al. 2005). For example, Dooley et al. (2001) identified that the aggressive behavior of a 3-year-old boy with autism was associated with transitions at school. Other studies have demonstrated that aggression occurs when stereotyped or ritualistic behaviors are interrupted, and is maintained by regaining access to these behaviors (Hagopian and Toole 2009; Hausman et al. 2009; White et al. 2011).

Disruptive and Destructive Behaviors Disruptive and destructive behaviors are behaviors that result in significant interruption, disruption, or destruction of the environment. Although all challenging behaviors of children with ASD possess the potential to disrupt the environment or cause damage to property (e.g., self-injurious head banging against a table during academic work), for the purposes of this chapter discussion will focus on those behaviors which are not typically classified as stereotyped movements, self-injurious, or aggressive behavior, such as inappropriate loud vocalizations, tantrums, noncompliance, banging on walls and other surfaces, throwing objects, tipping or knocking over furniture, and intentionally damaging or breaking property (Conroy et al. 2007; Kuhn et al. 2009;

Ozdemir 2008). While inappropriate vocalizations may technically be classified as vocal stereotypy, they often are considered disruptive, particularly in public or school settings (Ozdemir 2008; Scattone et al. 2002).

Surprisingly, disruptive and destructive behaviors, while constituting one of most common challenging behavior of persons diagnosed with ASD (Smith and Matson 2010), rarely are the sole focus of assessment or intervention. More often than not, these behaviors are included with other severe challenging behaviors (Harding et al. 2001; Kuhn et al. 2009). This may be due to the frequent co-occurrence of disruptive and destructive behaviors to other challenging behaviors, most notably aggression, suggesting these behaviors typically group together or are part of a similar response class (Fisher et al. 1998; Harding et al. 2001). In the development of the Baby and Infant Screen for Children with aUtism Traits (BISCUIT-Part 3: Matson, Boisjoli et al. 2009), scale items for disruptive and destructive behaviors loaded onto the factor associated with aggression, supporting that these behaviors may occur as a class of problems.

As a result of the overlap with other challenging behaviors, the prevalence of disruptive and destructive behaviors in children with ASD is difficult to estimate. Matson, Fodstad et al. (2009) report that 18.8 % of children 3 years of age and younger diagnosed with ASDs were reported by a caregiver as exhibiting moderate to severe impairment related to tantrum/conduct behavior. Although aggressive behavior was included in this category, endorsement for specific items associated with disruptive and destructive behaviors ranged from 18.1 (“Deliberately annoys others”) to 58.3 % (“Tantrums”). “Damages property” and “destroys others’ property” were endorsed at 28.2 and 24.9 %, respectively. Hattier et al. (2011) identified prevalence rates ranging from 24.5 to 37.0 % for a variety of disruptive and destructive behaviors (e.g., kicking objects, banging on objects, property destruction, repeated and unusual vocalizations) in a sample of 633 children of 3 years of age and younger diagnosed with ASDs. Similar prevalence rates have been reported in other investigations (Jang et al. 2011).

In general, the literature suggests that disruptive and destructive behaviors primarily operate in order to escape from aversive tasks; avoid transitions; obtain access to preferred items; gain the attention of others; and, avoid aversive sensory stimuli (Ebanks and Fisher 2003; Harding et al. 2001; Reed et al. 2009; Reese et al. 2005; Wilder et al. 2006). Other more unique findings have included individuals who engaged in disruptive and destructive behaviors to produce object pieces with which subjects engaged in stereotypy (Fisher et al. 1998) or for automatic reinforcement (Graff et al. 1999).

Assessment of Challenging Behaviors

Comprehensive and accurate assessment of challenging behaviors is integral in planning interventions and treatments for children with ASDs. Assessment should consider not only functional behavioral aspects of the challenging behavior, but also potential organic or psychiatric factors. For example, a challenging behavior may be associated with a medical condition, such as an gastro-intestinal problems (Peine et al. 1995); a psychiatric condition, such as a mood disorder (Hemmings et al. 2006; Rojahn et al. 2004); or may be exacerbated by a biological symptom that may require medication intervention, such as a sleep disorder (Braam et al. 2010; Wiggs and Stores 1996). Therefore, prior to behavioral assessment, it is advised that the child be evaluated by a pediatrician or psychiatrist who has experience with children with ASDs.

When it comes to assessing and intervening with challenging behavior displayed by individuals with autism, the most effective evidence-based approaches involve the principles of applied behavior analysis (Powers et al. 2011). ABA focuses on operant behavior relationships, behavior measurement, and when necessary an experimental analysis to verify a functional relationship (Baer et al. 1968). Interventions for reducing challenging behavior are most effective when preceded by a thorough assessment that determines the function of the challenging behavior (Herzinger and Campbell 2007). Functional behavioral assessment (FBA) is a multi-method approach for gathering information about antecedents, behaviors, and consequences to identify the function of challenging behaviors, which may consist of indirect and/or direct assessment methods (O'Neill et al. 1997).

Indirect Assessment Methods Indirect methods for assessing challenging behavior usually consist of interviews with caregivers and behavior rating scales. These methods vary based on the level of information that can be obtained on the child and the severity of the challenging behavior (Kern et al. 2005). The likelihood of obtaining valid information about challenging behaviors is optimized when multiple raters are involved. Information collected from indirect assessment methods is often the building blocks for developing working hypotheses about the functions of challenging behavior.

Interviews The initial step of assessment of challenging behavior is to conduct an interview to operationalize the challenging behavior, and develop an understanding of the behavior's history, the current sequencing of behaviors, and prior assessment and interventions that have been implemented. Semi-structured and structured interview forms often are preferable as they typically possess better inter-rater reliability. An example of a structured interview form is the Functional Assessment Interview (FAI) (O'Neill et al. 1997), which allows an interviewer to gain specific information about the child in a variety of settings (e.g., home, school, and/or community) and from multiple informants (e.g., teachers and parents). The FAI facilitates accurate descriptions and operational definitions of target behaviors, as well as exploration of the setting events, antecedents, and consequences surrounding challenging behavior. This information is used to develop summary statements regarding function of challenging behavior, and helps in treatment planning by emphasizing identification of alternative and desired behaviors.

Behavior-rating Scales A number of standardized assessment scales (checklists, questionnaires, and rating forms) can be used to identify challenging behaviors, and allow for a comparison of severity or frequency against same-aged peers. For example, the Childhood Autism Rating Scale—Second Edition (CARS2) (Schopler et al. 2010), Gilliam Autism Rating Scale—Second Edition (GARS2) (Gilliam 2006), and Baby and Infant Screen for Children with Autism Traits (BISCUIT) (Matson, Boisjoli et al. 2009) are screening tools that focus primarily on the diagnosis of the core features of ASD, but also include items that focus on challenging behaviors typical of this population.

Global behavior rating scales also can be used with children with ASDs, and include the Nisonger Child Behavior Rating Form (Lecavalier et al. 2004), Behavior Problems Inventory (Murphy et al. 2009), Aberrant Behavior Checklist (ABC) (Aman et al. 1985), Behavior Assessment Scale for Children—Second Edition (BASC-2) (Reynolds and Kamphaus 2004), and Child Behavior Checklist (CBCL) (Pandolfi et al. 2009). All of these forms are completed by caregivers and evaluate a broad range of challenging behaviors often characteristic of children with developmental disabilities or externalizing behavior disorders. However, with the exception of the ABC, there is a lack of specific items on these measures for the challenging behaviors of children with ASD.

The Autism Spectrum Disorder-Behavior Problems for Children (ASD-BPC) (Matson, Gonzalez et al. 2008) is the only published measure to focus specifically on common challenging behaviors displayed by children with Autistic Disorder, PDD-NOS, and Asperger's disorder (e.g., disruptions, aggressions, self-injury, and stereotypy). The ASD-BPC is an 18-item screening questionnaire that rates behaviors as "not a problem or impairment," "mild problem or impairment," or "severe problem or impairment," with each item loading on either an externalizing or internalizing scale. Results have shown the ASD-BPC has adequate levels of reliability (Matson and Rivet 2008), and moderate levels of convergent validity and discriminant validity when compared to scales from the BASC-2 (Mahan and Matson 2011).

Although identifying the topography and assessing the severity of challenging behaviors for children with ASD is important to assessment, particularly pre- and post-treatment effects, these measures do not directly evaluate the function of challenging behaviors. Several questionnaires exist that can be used to provide information about the functions of a challenging behavior including the Motivation Assessment Scale (MAS) (Durand and Crimmins 1988), Functional Assessment Screening Tool (FAST) (Iwata and DeLeon 2005), and the Questions About Behavioral Function (QABF) (Matson and Vollmer 1995). Psychometrics on the FAST have not yet been published despite its use in the field. However, the MAS and QABF have been extensively evaluated, though rarely with individuals under the age of five.

To summarize, indirect assessment methods quickly provide information about multiple behaviors. In many settings, due to limited resources and environmental supports, indirect assessments may be the only option available for use in evaluating challenging behavior. Primary limitations of indirect methods include obtaining information that is based on subjective opinion and memory, and techniques that do not allow for the direct observation and evaluation of contextual variables maintaining challenging behavior.

Direct Assessment Direct assessment involves the direct observation of behavior. These methods include descriptive and experimental techniques which evaluate relationships between environmental events and behavior. These procedures have the advantage of allowing the examiner to observe behavior in specific contexts, and provide a clearer display of the functional nature of the behavior. Procedures selected should take into account the environmental setting in which they will be employed, the context in which challenging behavior occurs, the intensity of the behavior, and the level of environmental supports that can be provided. For example, descriptive assessments may be more useful in classroom settings, while experimental analyses may be better suited for hospital and outpatient settings.

Observation Systems Scatter plots provide information about the occurrence of targeted challenging behaviors during specific time intervals (Touchette et al. 1985). By identifying times when the challenging behavior is likely to occur, one can then obtain additional information about environmental events contributing to challenging behavior (e.g., correlations can be viewed between challenging behavior and specific activities).

Two more direct methods of behavioral observation that provide specific information about the occurrence of environmental events surrounding challenging behavior are the antecedent-behavior consequence (Bijou et al. 1968) and interval recording methods (Cooper et al. 2007). The first method, ABC recording, involves detailing the (a) environmental conditions occurring before a behavior, (b) a description of the behavior, and (c) the consequences after the behavior. The second method, interval recording, consists of partial, whole, and momentary time sampling procedures. The observation method chosen for data collection will depend on the specific characteristics of the target behavior (i.e., duration or frequency), as well as the skill level and availability of data collectors. Although information obtained from naturalistic observations does not provide direct evidence of causation as in an experimental analysis, results obtained can be evaluated using conditional probabilities to further establish correlation (Hagopian et al. 2005; Martens et al. 2008).

Direct observation methods discussed thus far require little training and can be performed in the individual's natural environment. Primary limitations include reactivity of participants being observed, and the results being correlational instead of demonstrating causal relationships. To determine causal relationships, experimental functional analyses are needed test hypotheses about challenging behavior.

Functional Analysis Functional analysis (FA) procedures are evidence-based methods for identifying the variables that promote and maintain challenging behavior (Iwata, Dorsey et al. 1994). Specifically, FA procedures involve manipulating antecedents and consequences to identify the contextual stimuli that occasion and maintain challenging behavior. Decades of research has established FA procedures as the most valid identifying the function of challenging behaviors (Reeve and Carr 2000; Wacker et al. 1998), including determining whether a challenging behavior occurs to escape aversive tasks, activities, or individuals (negative reinforcement); access social attention, tangibles, or preferred activities (positive reinforcement); or obtain or alleviate internal stimulation (Hanley et al. 2003; Iwata, Dorsey et al. 1994). Additionally, FA has demonstrated efficacy in delineating the functions of challenging behaviors for young children with ASDs (O'Reilly et al. 2009; LaBelle and Charlop-Christy 2002; Perrin et al. 2008). At times, modifications to FA procedures are warranted to accommodate the specific needs of young children. For example, Kurtz et al. (2003) utilized caregivers in FAs, did not use the alone condition, provided extended attention in the attention condition, and used activities of daily living instead of academic demands in order to accommodate young childrens' developmental levels.

Despite its effectiveness in identifying functions of challenging behavior, FA methodology has some limitations. For example, the procedures are often expensive and time consuming. Additionally, FAs are mostly conducted in contrived settings by highly trained clinicians who are unfamiliar, and thus may confound results (Huete and Kurtz 2010). A standard FA does not allow for the naturally occurring stimuli (packages of interacting contextual variables) to occur in the participant's environment. In addition, there is argument as to whether the procedure is identifying the function of the behavior or establishing new functions (Rooker et al. 2011; Shirley et al. 1999), strengthening contingencies for challenging behavior, or measuring inexistent functions (i.e., is behavior self-stimulatory or due to withdrawal of opportunities for reinforcement; Iwata, Pace, Dorsey et al. 1994).

Multiple adaptations can be made to standard FA procedures to increase their effectiveness. For example, when the materials or time needed for a standard FA are not available, an alternative is a discrete-trial functional analysis (DTFA) (Sigafoos and Saggers 1995). DTFA is a brief experimental method for assessing challenging behavior in a child's natural environment within their daily routine (Bloom et al. 2011). Procedures of a DTFA are easier to implement than a standard FA and less time consuming (LaRue et al. 2010), and may provide more accurate results by allowing parents and other caregivers to participate easily in the FA process (Kurtz et al. 2003; Ringdahl and Sellers 2000).

When undifferentiated results are obtained from a standard FA, it may be fruitful to combine approaches by utilizing a descriptive assessment to obtain additional information for alternative hypotheses (Borrero et al. 2004). Information obtained can then be used to alter FA procedures to investigate idiosyncratic variables that maintain challenging behavior (Tiger et al. 2009) such as access to ritualistic behaviors (Hausman et al. 2009) and adult compliance with mands (Bowman et al. 1997).

Summary Within direct assessment methods, FAs are the most rigorous methodological procedures for determining causal relationships concerning challenging behavior. For children with chronic challenging behavior that has been resistant to prior assessment and intervention procedures, or behaviors that are too dangerous to assess in the natural setting, an analogue FA is the most plausible approach for assessing challenging behavior (Hanley et al. 2003). However, across methods of assessment, it may behoove professionals working with children with challenging behavior to utilize descriptive and indirect assessment approaches to better understand how a child's behavior functions in the natural environment, and to control for idiosyncratic variables that may be affecting behavior.

In some situations indirect assessments are more appropriate for evaluating challenging behavior. For example, children with ASDs whose intellectual abilities are more typical may have reactivity to being observed in experimental FAs. In these situations, it may be prudent to rely on indirect assessments, which have shown higher rates of sensitivity and specificity with FA results than descriptive assessments (Hall 2005; Paclawskyj et al. 2001; Tarbox et al. 2009; Thompson and Iwata 2007). Regardless of the assessment procedure used, the emphasis of behavioral assessment should be on identifying the function of the challenging behavior for subsequent interventions.

Psychiatric Assessment Challenging behaviors of persons with ASDs often are associated with psychiatric symptomatology, and overshadowed by or erroneously attributed to the presence of the ASD or cognitive impairment (Reiss et al. 1982). In fact, children and adults with ASDs are at increased risk of comorbid psychiatric disturbance with prevalence estimates as high as 74% (Brereton et al. 2006; Mattila et al. 2010). As a result, it is important to have a full psychiatric evaluation, particularly in situations where the challenging behavior is chronic, severe, and not responsive to behavioral interventions with a focus on details about changes in the child's daily routine, school performance, home behavior, habits, interests, sleep habits, appetite, and mood (Matson and Dempsey 2008; Scahill 2008). In addition, it is advised that the evaluation be performed by a physician who is knowledgeable of developmental disabilities, and more specifically ASDs. For example, agitation, and resulting aggression, may occur in response to clear social contingencies, but it is also a symptom of psychiatric disorders such as anxiety, mood disorder, psychosis, or agitated catatonia. In addition, agitation can be part of a somatic disorder such as akathisia (a side effect of first or second generation antipsychotics and SSRIs), or due to the adverse effect of a certain medication, as often occurs with over-the-counter medications (e.g., dyphenidramine). Other causes of agitation might be pain, fatigue, malaise or frustration. The psychiatrist should be able to rule out these various potential factors, and should consider basing diagnostic decisions on criteria defined in the Diagnostic Manual-Intellectual Disability (DM-ID) (Fletcher et al. 2007), as well as the DSM-IV-TR (APA 2000). The DM-ID is an adaptation of the DSM-IV-TR diagnostic criteria for the cognitively or language-impaired population, which includes ASDs.

A significant portion of children with ASDs are nonverbal or unable to communicate their symptoms. In some instances, such as inpatient hospital settings, a psychiatrist may be able to utilize direct observation techniques to assess medication effects. However, most children with ASD and challenging behaviors receive psychiatric care through outpatient settings, where only caregiver report and brief child observations are available. Therefore, gathering information from alternative sources, such as parents or caregivers, is necessary. To aid in more accurate report data, caregiver-report questionnaires and checklists are often used to assess challenging behaviors and evaluate the effectiveness of psychopharmacological interventions, including the ABC (Aman et al. 1985), particularly the irritability, hyperactivity, stereotypy, and inappropriate speech subscales; Children Psychiatric Rating Scale (CPRS) (Pfefferbaum-Levine and Overall 1983); the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS) (Scahill et al. 1997); and, the Clinical Global Impressions-Improvement Scale (CGI-I) (Busner and Targum 2007). In practice, however, a thorough psychiatric interview that includes family history, current and past medical history, medications being administered, description of school and social environment, severity of the behaviors, and the impact of behavior on the patient's ability to function in activities of daily life, is irreplaceable.

Interventions and Treatment for Challenging Behaviors

Numerous interventions and treatments have been described in the literature for challenging behaviors in children with ASDs. The two most prevalent forms of treatment are behavioral and psychopharmacological interventions. Behavior-

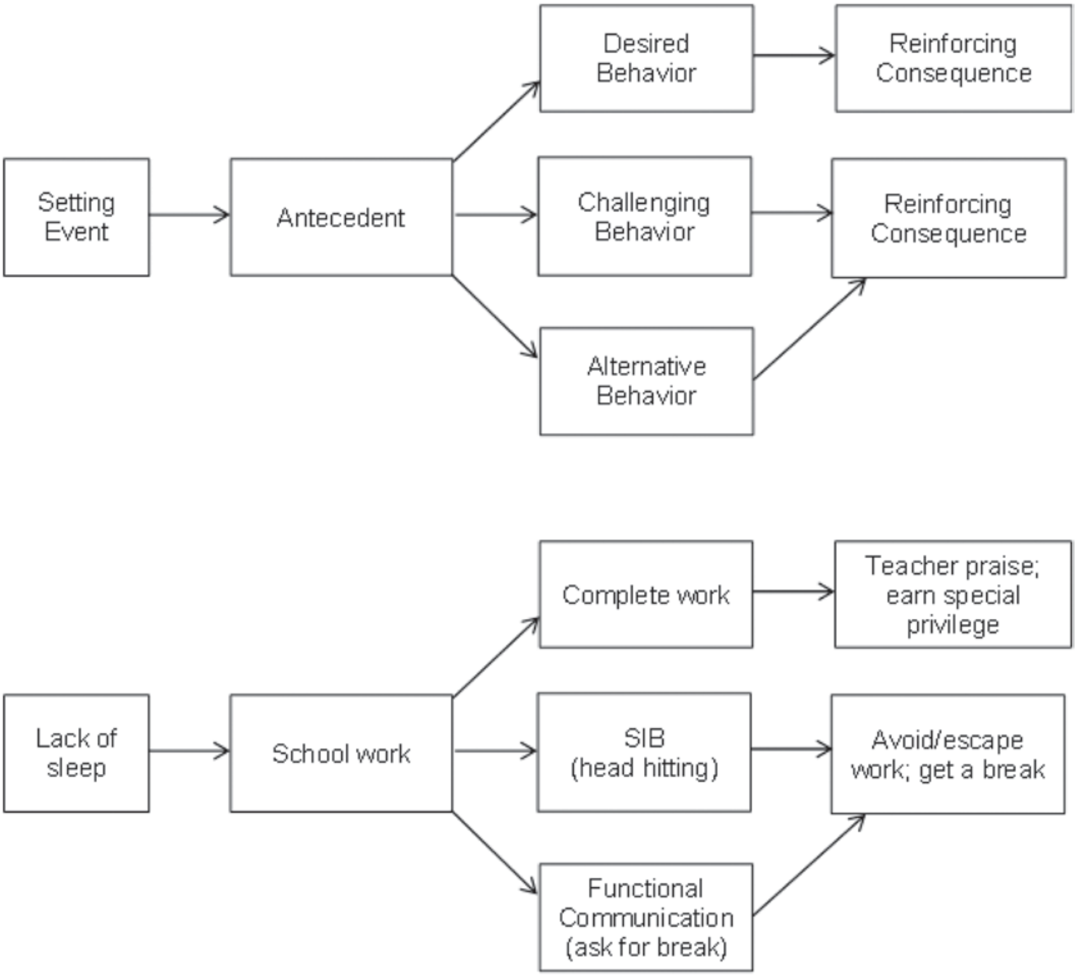

Fig. 26.1 Competing Behavior Model and example. (Adapted from O'Neill et al. 1997)

al interventions typically employ the methods of applied behavior analysis, which seek to identify and alter the environmental antecedent(s) that set the occasion for the challenging behavior, and the consequences that serve to maintain the behavior. This can be accomplished in many ways, but most interventions follow a competing behavior model (see Fig. 26.1; O'Neill et al. 1997), which seeks to alter environmental antecedents and consequences in order to decrease the challenging behavior, while increasing an alternative and/or desired behavior. Psychopharmacological interventions often target underlying psychopathology. This mode of treatment is described in another chapter; therefore, for this chapter, discussion will be limited to psychiatric/ pharmacological interventions that target specific challenging behaviors or symptoms associated with those behaviors.

It should also be noted that most children diagnosed with ASDs who exhibit challenging behaviors receive both behavioral and pharmacological treatments. However, in most cases, these services are separate and not collaborative or coordinated. This is reflected in the treatment literature, where medication interventions for challenging behaviors usually are reported separately and not in collaboration with behavioral treatments. Although research in the treatment of most other psychiatric populations emphasizes combining medication and behavioral interventions, such as depression (Calati et al. 2011), there are few evidence-based reports of combined interventions for challenging behaviors of children with ASDs (Aman et al. 2009; Frazier et al. 2010). Results of these studies generally demonstrate improved behavioral outcomes and reduced use of psychotropic medications with combined interventions compared to medication alone. While there is a substantial need for research examining the combined effects of behavioral and medication interventions for challenging behaviors in young children with ASDs, data from other populations and problems suggest that a combined approach is warranted.

Behavioral Interventions

Extinction One of the most basic and direct interventions for challenging behavior, extinction operates by withholding the reinforcer(s) previously delivered upon the occurrence of the behavior (Catania 1998). As a result, the functional link between the challenging behavior and the reinforcing consequence is weakened, thus resulting in a decrease in the behavior. For example, extinction may be used in a situation where a caregiver has a history of providing a toy to a child contingent on the child's self-injurious head banging by having the caregiver withhold the toy on future occurrences of SIB. This should result in a gradual decrease in the contingency between SIB and the reinforcer.

However, extinction procedures are only effective when matched to the function of behavior (Iwata, Pace, Cowdery et al. 1994; Richman et al. 1998). The previous example of the caregiver withholding a toy in response to SIB would be appropriate if SIB was maintained by access to the toy (i.e., social positive reinforcement). However, if SIB was actually maintained by escape or avoidance from nonpreferred demands, then withholding delivery of a toy likely would not affect SIB responding. Instead, extinction would have to take the form of escape extinction, where escape from the demands would not be allowed contingent on SIB. In general, extinction is applied in three ways, depending on behavioral function, including (1) withholding or minimizing a consequence when the behavior is maintained by social positive reinforcement, (2) by not allowing avoidance or escape as a consequence when the behavior is maintained by social negative reinforcement, and (3) by attenuating or eliminating the sensory consequence when the behavior is maintained by automatic reinforcement, often referred to as "sensory extinction" (Rincover 1978).

Extinction rarely is utilized alone, and most often is used in conjunction with other interventions (Vollmer, Sloman et al. 2009). The inclusion of other interventions, such as functional communication and differential reinforcement procedures, aids in reducing the temporary increases in challenging behavior associated with extinction known as "extinction bursts" (Lerman and Iwata 1996). Extinction bursts can be especially problematic when treatment is for severe challenging behaviors, such as SIB or aggression, where even temporary increases in frequency or intensity may be unacceptable. In addition, the inclusion of other interventions with extinction not only targets reducing the challenging behavior, but also increasing an alternative or desired appropriate behavior, which usually is a goal of behavioral interventions (O'Neill et al. 1997). For example, Hausman et al. (2009) combined extinction with functional communication in the treatment of SIB, aggression, and property destruction in a 9-year-old female with autism, whose challenging behaviors were maintained by access to rituals. Extinction targeted eliminating the functional link between the challenging behaviors and access to rituals, while an appropriate alternative behavior (i.e., communication) was established that allowed for access to rituals.

Differential Reinforcement The purpose of differential reinforcement (DR) is to increase behaviors of one response class (desired behavior) through reinforcement and decrease behaviors of another response class (challenging behavior) through extinction (Cooper et al. 2007). A few examples of differential reinforcement procedures include reinforcer delivery for alternative behavior (DRA), behavior that is incompatible with the problem behavior (DRI), and no occurrences of problem behavior after a predetermined amount of time (DRO). When implementing DRA or DRI, it is important to consider the density of the schedule of reinforcement, magnitude, quality, and swiftness with which the reinforcer can be delivered, and the physical and cognitive effort of the response required (Halle et al. 2005). These factors are essential for demoting problem behavior in the response class hierarchy.

The goal of DR is to render the child's problem behavior inefficient so that more socially acceptable behaviors can occur. With instances where the behavior is unable to be eradicated or the prior DR procedures are not completely feasible (e.g., the behavior occurs at too high rate), differentially reinforcing low rates of the behavior (DRL) may be more appropriate initially so the child can contact the contingencies in place, until further fading can occur. Additionally, extinction may not always be possible due to the severity of the problem behavior (e.g., aggression), and as a result, it may be necessary to manipulate the parameters surrounding the schedule of reinforcement to make it more favorable for emitting acceptable behavior instead of problem behavior (Athens and Vollmer 2010; Piazza et al. 1997). Also, DR schedules can be difficult to implement due to the complexity of the treatment packages (e.g., having to monitor specific periods of time where the behavior does not occur).

Functional Communication Training Functional communication training (FCT) is a well-established intervention for challenging behaviors of children with ASDs (Kurtz et al. 2011; Mancil 2006). FCT is a differential reinforcement procedure that operates on the assumption that challenging behaviors are forms of communication (Durand 1990). As such, FCT involves teaching an individual to use an appropriate form of communication as a replacement for the challenging behavior (Carr and Durand 1985). For example, Matson, LoVullo et al. (2008) utilized FCT in the treatment of aggression of an 11-year-old female with autism by teaching her to hand a communication card to an adult when she needed help.

In order to effectively use FCT, the function of the challenging behavior needs to be discerned. Therefore, prior to FCT, the function of the challenging behavior should be identified via a functional behavioral assessment (Durand and Merges 2001; Tiger et al. 2008). Afterwards, an appropriate communicative response that will serve the same function as the challenging behavior needs to be identified and taught to the individual. Several factors should be taken into consideration when deciding on the communication response. For example, the individual should possess adequate motor skills to produce the communication response efficiently (Tiger et al. 2008). Response effort at producing the communication response should be low, at least during skill acquisition (Horner and Day 1991); high effort responses may be best for generalization purposes (Hernandez et al. 2007). In addition, a decision will need to be made between a topography-based system, such as verbal language or sign language, and a selection-based system, such as picture exchange. Topography-based systems are more portable, and eliminate the potential difficulty of an individual having to discriminate among various pictures, as is the case with selection-based systems. However, selection-based systems seem to facilitate acquisition of the communication response quicker, and may be better in situations where the individual lacks verbal language or has difficulty with fine motor skills (Horner and Day 1991; Tiger et al. 2008).

As an intervention, FCT rarely is used alone, and more often is part of a treatment package. Most often, FCT is paired with extinction or a punisher, in which case the functional reinforcer is delivered contingent on the communication response, while all challenging behaviors are ignored, or result in an aversive consequence (e.g., time out). Hagopian, Fisher, Sullivan, Acquisto, and LeBlanc (1998) reported that FCT alone was not effective in treating the severe challenging behaviors of 21 individuals with IDDs, and was only effective when paired with extinction or a punishment. However, in some circumstances, FCT only can be effective, usually when the schedule of reinforcement for the communication response is denser than that of challenging behavior (Kelley et al. 2002; Worsdell et al. 2000), but also when the schedules are similar (Casey and Merical 2006).

Noncontingent Reinforcement Noncontingent reinforcement (NCR) is the delivery of preferred items or reinforcers independent of behavior (Cooper et al. 2007). Thus, NCR could be defined as "free rewards." Due to extinction and satiation components involved in NCR, it is hypothesized that the child will be less motivated to engage in problem behavior (Vollmer and Borrero 2009). NCR can be delivered on a variable or fixed time schedule, and the reinforcers provided may or may not be functionally related to the problem behavior. For example, if a child has an attention function, an adult may provide the child with attention every 30 s regardless of the child's behavior, or provide the child with access to toys while attention from the adult is unavailable.

NCR is a commonly used intervention for treating challenging behavior for numerous reasons. First, this procedure does not require the child to emit a response (i.e., DRA) or to go for extended periods of time without emitting a problem behavior (DRO) in order to obtain reinforcement (Hagopian et al. 1994). Second, NCR can be useful for interrupting or preventing automatically maintained behavior by providing alternative sources of reinforcement (Favell et al. 1982; Roscoe et al. 1998). Third, logistically, NCR is considered to be easier to implement than other behavior strategies such as extinction or DR procedures because there is an exact schedule for delivering reinforcement and few criteria for administration. Finally, NCR may be most appropriate for individuals who engage in high rates of aggressive, disruptive, or SIB that is difficult to block or place on extinction (e.g., a child that is stronger than his/her care provider).

There are some considerations that must be addressed when using NCR. For example, it is possible to "accidentally" strengthen the relationship between problem behavior and the delivery of reinforcement, if a problem behavior occurs shortly before the delivery of the reinforcer (i.e., adventitious reinforcement). In such situations, it may be helpful to use a combination of NCR and DRO (Vollmer et al. 1997), with reinforcement still delivered on a schedule, but only provided after a specific amount of time has passed without a problem behavior (e.g., 5 s).

Punishment Although antecedent and function-based treatments do work for reducing the problem behavior of a majority of children, it may be necessary to use punishment for some to obtain clinically significant reductions (Hagopian et al. 1998). Punishment involves the occurrence of environmental stimuli following a behavior that decreases the frequency of that behavior in the future (Lerman and Vorndran 2002). Positive punishment involves the delivery of a stimulus (e.g., verbal reprimand, overcorrection, response blocking, contingent demands) while negative punishment involves the removal of a stimulus that is typically a reinforcer (e.g., response cost or timeout); both procedures have been shown to be effective in decreasing problem behavior (Falcomata et al. 2004; Hagopian et al. 2002; Hanley et al. 2005).

Commonly used punishment procedures vary from mild verbal reprimands to full restraint and will vary based on the behavior that needs to be decreased. Punishment selected should be functionally related to the problem behavior. For example, timeout from reinforcement would be more appropriate for a child who engages in problem behavior to obtain attention rather than a child who engages in problem behavior to escape demands. Regardless of the function, if a behavior is severe enough that it frequently causes injury (e.g., head slapping or hand biting) and/or a child is at risk for permanent damage (e.g., retinal detachment or infection), it may be necessary to stop the behavior from occurring immediately with more stringent measures (e.g., a basket hold).

Factors to consider when providing punishment include the immediacy, consistency, and magnitude with which the punisher can be delivered, as well as the history of the problem behavior and implementation of prior punishers (Lerman and Vorndran 2002). Perhaps most importantly, it is critical to assess the social validity of the procedures prior to their implementation, particularly since there has been a strong movement against the use of punishment (Carr et al. 2002). If care providers or school staff do not agree with the punishment procedures suggested, treatment integrity will most likely be low. Additionally, it is recommended to conduct a punisher assessment to determine the actual punishing effects of the procedures, and the acceptability to care providers.

The primary flaw of punishment is that it does not teach what behavior the child should be emitting. For this reason, when implementing punishment procedures it is ideal to combine the punisher with a dense schedule of alternative reinforcement in an attempt to increase the more acceptable behavior. If punishment is not implemented consistently, it may prove ineffective. Thus, it is recommended that initially it be implemented on a fixed ratio 1 schedule of reinforcement, before being faded.

Protective Equipment and Restraint Procedures Protective equipment and restraint include a variety of procedures that have one common goal: to suppress, inhibit, or increase the response effort required to engage in a challenging behavior. Included in this category are procedures that involve physically holding a person to inhibit movement, such as basket hold timeout; procedures that employ devices or equipment that seek to immobilize or protect an individual from certain behaviors, such as the use of padded helmets, arm splints, protective clothing, gloves, wrist cuffs, and wrist weights; and, chemical restraint procedures, which use psychotropic medications to sedate an individual (Matson and Boisjoli 2009). As chemical restraint is almost universally opposed and only considered under the most extreme circumstances (Matson and Boisjoli 2009), and mechanical restraint for crisis intervention purposes often lacks therapeutic value, the focus of this section will be on the use of protective equipment in therapeutic interventions.

Surprisingly, while the use of protective equipment and restraint procedures are fairly common in treating challenging behaviors, there is comparatively little recent published research on it, especially with young children where its use is less prevalent. This might be due to the stigma associated with protective equipment, as well as increased emphasis on identifying alternative, nonrestrictive treatments. Additionally, protective equipment and restraint procedures probably are best conceptualized as facilitators of intervention as opposed to interventions themselves. While protective devices, such as arm splints, conceptually may serve the function of extinction by restricting or attenuating the consequences of a behavior, often they are used with and to allow for the success of other interventions, such as NCR programs and enriched environments (Roscoe et al. 1998).

Much of the research on protective equipment has focused on its use in sensory extinction treatments of SIB (Rincover 1978), particularly the use of arm splints and helmets for the treatment of head hitting. Moore, Fisher, and Pennington (2004) reported, treating the SIB of a 12-year-old girl with autism by utilizing a combination of a protective helmet, rigid arm sleeves, and padded gloves that eliminated or attenuated the assumed positive sensory consequences of SIB. However, the use of restraint procedures, particularly prolonged use, can be associated with a host of negative side effects, including interference with motor development (Lovaas and Simmons 1969), inhibition of adaptive skills (Wallace et al. 1999), social stigma (Rojahn et al. 1980), and the emergence of new forms of challenging behaviors (Fisher et al. 1997). Therefore, when using protective equipment, a plan for fading, gradually reducing, and eventually eliminating the restraint is necessary (Fisher et al. 1997). In many circumstances, protective devices are used where the padding or rigidity of the device can be decreased gradually and incrementally (Fisher et al. 1997; Pace et al. 1986). Additionally, the use of protective equipment noncontingently or contingently in response to challenging behavior has been evaluated with results suggesting that noncontingent use serves a sensory extinction function (Moore et al. 2004), while contingent application seems to function as punishment (Mazaleski et al. 1994).

The use of protective equipment and restraint procedures is controversial and has come under increased scrutiny in recent years (Day et al. 2010; Matson and Boisjoli 2009). There is a clear movement to either reduce or eliminate the use of protective equipment and other restraint procedures with persons diagnosed with IDDs and ASDs (Day et al. 2010; Miller et al. 2006). However, even though there has been an emphasis on using alternative, nonrestrictive procedures to treat challenging behaviors in persons with ASDs, particularly those that reinforce appropriate alternative behaviors, the use of restrictive procedures occasionally is warranted (Matson and Boisjoli 2009). Therefore, the legitimate concerns regarding the rights and welfare of persons with challenging behaviors must be balanced with the risk these behaviors present to those individuals (Day et al. 2010). For example, the use of a protective device likely is warranted when the challenging behavior poses an immediate and imminent danger to the individual, such as self-injurious eye poking that may result in permanent eye damage or blindness.

At the center of the decision to use protective equipment and restraint procedures is determining whether their use is merely one of convenience for caretakers, for safety of the individual and others, and/or for treatment purposes (Matson and Boisjoli 2009). As a result, practitioners and researchers have sought to delineate guidelines and procedures for not only the effective, but also ethical use of restraint procedures (ABAI 2010; Matson and Boisjoli 2009). In general, restraint should only be employed with the child's welfare as the primary goal and with the consent of the child's caregiver(s); only the safest and least restrictive procedures that are effective should be used; restraint should be used only as a last resort and after extensive evaluation of nonrestrictive procedures has justified their use; restraint should be based on the results of a functional assessment and used in conjunction with other reinforcement-based procedures in a planned manner within the clear goals of a behavior intervention or treatment plan; and restraint procedures should be implemented by trained persons, overseen by a mental health professional, such a licensed psychologist or certified behavior analyst, and monitored closely for their effectiveness using objective data (ABAI 2010; Day et al. 2010; Matson and Boisjoli 2009).

Psychiatric Treatments While stereotypy, SIB, aggression, and disruptive/destructive behaviors are the focus of this chapter, it should be noted that children with ASDs often are referred for other behavioral problems, such as hyperactivity and sleep disturbance (Singh et al. 2011). These behavior problems may be the sole focus of intervention, or may be directly or indirectly related to another challenging behavior. For example, sleep problems have been associated with increased reports of aggression, destructive behavior, and stereotypies in infants and young children with ASDs (Matson et al. 2011). In these instances, psychiatric treatments usually target the specific symptoms, such as using melatonin for sleep (Rossignol and Frye 2011), or psychostimulants, such as methylphenidate (Ritalin^{TM}), or alpha agonists, such as clonidine (Catapres^{TM}) or guanfacine (Tenex^{TM}) for hyperactivity and other symptoms of ADHD (Ghuman 2008; Handen et al. 2011; Quintana et al. 1995; Scahill et al. 2006).

Psychopharmacological interventions may be used to treat an entire suspected psychiatric disturbance, a specific behavior as a symptom of a psychiatric diagnosis, or a behavior occurring in the absence of a psychiatric diagnosis. For the purposes of this chapter, research will be presented for psychiatric interventions for specific behaviors regardless of the possibility of the behavior being part of a psychiatric disturbance, as such is reported elsewhere in this book. However, as previously mentioned, prior to intervention, it is of paramount importance to rule out the possibility of these challenging behaviors being a symptom of a psychiatric disorder. In these instances the therapeutic approach may differ with emphasis on treating the underlying disorder, as opposed to treating a symptom or behavior. For example, a child whose aggressive behaviors are related to an anxiety disorder likely would receive a different medication than if the aggression was related to a psychotic disorder or frustration from difficult academic demands.

Although there is a long history of and need for psychopharmacological interventions to treat challenging behaviors in children with ASDs, there are several limitations in the research literature that should be acknowledged. First, there are few well-controlled studies supporting their use (Matson and Dempsey 2008). In fact, only two medications are Federal Drug Administration (FDA) approved for symptoms related to autistic disorder, both for treatment of irritability: aripiprazole (Abilify^{TM}) and risperidone (Risperdal^{TM}) (Blankenship, Erickson, Stigler et al. 2010; Singh et al. 2011). The majority of published research reports on off-label use of medications, and more often than not these studies are "open label," which lack appropriate controls (Matson and Dempsey 2008). Second, medication effects typically are assessed via caregiver report on a standardized measure, such as the ABC (Aman et al. 1985), which are prone to subjective bias. Studies are needed that use direct measures of behavior, which would provide better indicators of improvement. Third, several different standardized measures have been used to assess medication effects, making it difficult to draw comparisons across studies for similar medications. Finally, challenging behaviors are not always the focus of medication interventions. Many medication studies target core, global features of autism or larger psychiatric symptoms, such as mood or anxiety. While many studies report global improvements in autism and psychiatric symptoms, the impact on challenging behavior alone is not always clear.

As a result of these limitations, psychiatrists are challenged with basing their understanding of medication utility on a less than optimal body of research and more often on case study reports, and sometimes must refer to reported results and clinical trials of medications used in the general population for similar symptoms to guide their decisions. To complicate matters, children with ASDs often present with multiple challenging behaviors which may require multiple medications for intervention (Carlson et al. 2006). Delineating the effects (both positive and adverse) of one or more medications on one or more challenging behaviors make the job of the psychiatrist even more difficult.

The most common medication classes used with ASD populations include psychostimulants, antidepressants, antipsychotics, mood stabilizers, and alpha agonists (Blankenship, Erickson and McDougle 2010; Handen and Lubetsky 2005; Matson and Dempsey 2008; Singh et al. 2011). As a comprehensive review is beyond the scope of this chapter, the following will present only a brief overview of the various medications used to treat challenging behaviors of children with ASDs. For more comprehensive, detailed reviews, the reader is directed to the following resources: Carlson et al. 2006; Handen and Lubetsky 2005; Matson and Dempsey 2008; Singh et al. 2011; Sweeney et al. 1998.

SIB and Stereotypy Several medications have been used to treat stereotypies and SIB, including antipsychotics and mood stabilizers (Handen and Lubetsky 2005). Psychiatrically, stereotypy and SIB often are understood as automatically maintained, compulsive behaviors (Hollander et al. 1998); therefore, the research primarily has focused on antidepressant medications used to treat obsessive compulsive disorder, including selective serotonin reuptake inhibitors (SSRIs), such as citalopram (Celexa^{TM}) and fluoxetine (Prozac^{TM}), and tricyclic antidepressants, such as clomipramine (Anafranil^{TM}). In general, the results of open label studies and case studies using antidepressants have been mixed. Clomipramine, which has been the gold standard for treatment of obsessive compulsive disorder, has been shown to decrease repetitive, ritualistic, and compulsive behaviors in children and adolescents with autism (Gordon et al. 1993; McDougle et al. 1992). Other studies have failed to support these findings and have reported adverse side effects, including fatigue, nausea, tremor, tachycardia, and insomnia (Remington et al. 2001; Sanchez et al. 1996). At least one study observed an increase in SIB with use of clomipramine (Magen 1993).

SSRIs increasingly are used to treat repetitive behaviors in children with ASDs. Fluoxetine (Prozac^{TM}), fluvoxamine (Luvox^{TM}), sertraline (Zoloft^{TM}), citalopram (Celexa^{TM}), and venlafaxine (Effexor^{TM}) all have been reported in the treatment of children with ASDs, and results have been promising. Fluoxetine and fluvoxamine both have been reported to reduce repetitive, compulsive, and ritualistic behaviors (Peral et al. 1999; Posey et al. 2006). Fewer studies of SSRIs have reported positive effects on SIB. One report documented reductions in SIB following the use of fluvoxamine (Yokoyama et al. 2002), but its limited benefit may be offset by concerns over side effects (McDougle et al. 2000). Paroxetine also has been reported to reduce SIB (Posey, Litwiller et al. 1999; Snead et al. 1994). However, in many of these studies, reductions in stereotypy and SIB were modest and not all subjects responded positively to the medications (King et al. 2009). In many instances, adverse side effects were reported, including agitation, anxiety, insomnia, hyperactivity, restlessness, and appetite loss (Cook et al. 1992; Peral et al. 1999).

One other medication that has received significant attention for treatment of SIB is naltrexone (Trexan^{TM}), an opiate antagonist. Naltrexone has been used under the hypothesis that SIB is maintained by automatic positive reinforcement in the form of the release of endogenous opiates (Sweeney et al. 1998). The action of naltrexone is to block the effect of the endogenous opiates, therefore removing the reinforcing consequence of SIB. In a review of the literature that included non-ASD subjects and adults, Symons, Thompson, and Rodriguez (2004) reported that 80% of subjects evidence reductions in SIB following use of naltrexone, with 47% demonstrating reductions as high as 50% from baseline rates. Case studies of subjects with ASD have reported similar findings (Chabane et al. 2000), but these have not been supported by clinical trials (Campbell et al. 1993).

Irritability/Aggression/Property Destruction/Disruptive Behavior Antipsychotics, or neuroleptics, have been the most often used medications for treatment of externalizing behaviors (i.e., irritability, aggression, property destruction, and disruptive behaviors; Singh et al. 2011). Typical, or first generation, antipsychotics, such as haloperidol (Haldol^{TM}), have been used in the past successfully to reduce severe externalizing symptoms in children with ASDs (Anderson et al. 1984). However, their use has declined in recent years due to concerns over severe adverse side effects, such as tardive dyskinesia and extrapyramidal problems, such as akathisia, tremors, and dystonic reactions (Campbell et al. 1987; Handen and Lubetsky 2005).

More recently, atypical, or second generation, antipsychotics have become increasingly used for externalizing behaviors because of their demonstrated effectiveness and better adverse effect profiles. Included in this class of medications are risperidone, aripiprazole, quetapine (Seroquel^{TM}), olanzapine (Zyprexa^{TM}), ziprasidone (Geodon^{TM}), and clozapine (Clozaril^{TM}). Collectively, all of these medications appear useful in the treatment of externalizing behaviors in children with ASDs, but the research support often is inconsistent with as many as half or more of participants in some studies either showing no response to the medication, or experiencing adverse side effects leading to discontinuation of the medication (Handen and Lubetsky 2005; Matson and Dempsey 2008; Singh et al. 2011). Risperidone and aripiprazole have the distinction of being the only medications in this class which are FDA approved for the treatment of irritability and aggression in children with autistic disorder, and have been the most researched. The evidence appears strongest for risperidone with numerous studies, including case reports, open label studies, and double-blind, placebo-controlled studies demonstrating significant reductions in irritability, aggression, tantrums, and other destructive and disruptive behaviors (Demb 1996; Findling et al. 1997; Shea et al. 2004). In a two-part study by the Research Units on Pediatric Psychopharmacology Autism Network (McCracken et al. 2002; RUPPAN 2005), children with ASDs taking risperidone showed significant improvement in measures of irritability, tantrums, and aggression over a placebo-control group. The improvements for the risperidone group persisted for 6 months, and relapse of symptoms was observed with the implementation of a placebo phase following the risperidone phase. Risperidone also has been used successfully to treat irritability and aggression in children with ASD as young as 2 years of age (Boon-Yashidi et al. 2002; Posey, Walsh et al. 1999). Few severe side effects have been reported in these studies, with the most common side effects being weight gain and sedation (Singh et al. 2011).

Aripiprazole also has been demonstrated to reduce irritability and aggression in children with ASDs (Owen et al. 2009; Stigler et al. 2004). Stigler et al. (2009) reported that 88 % of subjects with ASDs ages 5–17 years demonstrated improved symptoms on measures of irritability, aggression, and tantrums in a 14 week, open label study of aripiprazole. However, other reports have only documented improvement with aripiprazole in one third to half of subjects, and poorer outcomes for children diagnosed with ASDs, prompting calls for more well-controlled studies to support its use (Masi et al. 2009; Valicenti-McDermott and Demb 2006). Most studies report fewer and usually milder adverse side effects, such as agitation and sleepiness, with aripiprazole (Masi et al. 2009; Singh et al. 2011; Valicenti-McDermott and Demb 2006); however, more serious side effects, such as tremor, akathisia, and facial dyskinesia, have been noted (Marcus et al. 2009; Valicenti-McDermott and Demb 2006).

In addition to antipsychotics, medications used to treat mood disorders in the general population, such as anticonvulsants and antidepressants, have been used to treat irritability and aggression in persons with ASD. Antidepressants would appear to be effective, low-risk options for children with ASDs; surprisingly very few studies have evaluated their use in this group. Clomipramine, fluoxetine, fluvoxamine, sertraline, and paroxetine all have been reported to reduce irritability, anger, tantrums, and aggression in children with ASDs (e.g., Gordon et al. 1993; Cook et al. 1992; Yokoyama et al. 2002; Steingard et al. 1997; Posey, Litwiller et al. 1999). While the results appear promising, additional well-controlled studies are needed to evaluate their short and long-term benefit. For example, in one study, Steingard et al. (1997) found reduced aggression for eight of nine subjects using sertraline, but these effects lasted only 3–7 months for three subjects.

Anticonvulsants are commonly used to treat mood instability for persons diagnosed with bipolar disorder. As such, they have been evaluated for mood symptoms, such as agitation and aggression, with children with ASDs. Valproic acid (Depakote^{TM}) is one of the more common anticonvulsants and has produced mixed results. Hollander et al. (2010) reported a 62.5 % positive response rate for irritability on the CGI compared with placebo using divalproex sodium. Helling et al. (2005), though, did not find clinical improvement on the irritability subscale of ABC for 30 subjects ages 6–20 years. Other anticonvulsants, including carbamazepine (Tegretol^{TM}), lamotrigine (Lamictal^{TM}), topiramate (Topomax^{TM}), oxcarbazepine (Trileptal^{TM}), and levetiracetam (Keppra^{TM}) have little research supporting their use in treating externalizing behaviors of children with ASD, and are associated with numerous adverse side effects (Belsito et al. 2001; Handen and Lubetsky 2005).

Summary

Although not a core aspect of ASDs, challenging behaviors, including stereotypies, self-injury, aggression, and disruptive/destructive behaviors frequently are observed and likely have their origins in early childhood, but often are overlooked or dismissed as transient until they cause significant problems, such as injury to the individual or others, or damage to property. As a result, there is a growing emphasis on early identification and intervention of these behaviors for children at risk for or exhibiting early signs of ASDs, especially since these behaviors often persist into adulthood, interfere with skill development, and are associated with several adverse outcomes for the individual. Given their severe nature, children presenting with challenging behaviors should be evaluated as early as possible by both a behavioral specialist (e.g., psychologist or certified behavior analyst) and psychiatrist, both of whom should have expertise in assessing and treating children with ASDs. Behavioral and psychiatric assessment techniques have evolved in recent years that are sensitive in identifying the nature and function of these behaviors, which leads to more successful treatments. Furthermore, behavioral and psychiatric interventions are available, which have proven efficacious in the treatment of these behaviors in young children. However, more, well-controlled studies to substantiate the use of several medications with this population are needed. In addition, there is a need for research that evaluates combined and coordinated behavioral and psychiatric interventions, which findings from studies with others disorders (e.g., ADHD, depression) support as the most effective treatments.

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Mental Health Disorders in Young Children with Autism Spectrum Disorders

27

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Keywords
Anxiety · Depression · Attention deficit

It has been well understood for some time that children with autism spectrum disorders (ASD) experience high rates of behavior and emotional problems (e.g., Rutter et al. 1967; Simmons 1974; Wing 1981), but the past decade has seen a growing interest in the topic. There are obvious clinical reasons for this increased interest. These problems can negatively impact one's learning and daily activities and are associated with greater caregiver stress (Lecavalier et al. 2006). The additional supports needed to manage these problems often translate to a greater psychological and financial burden on families (Cidav et al. 2012). Long-term implications of psychopathology can include limited employment opportunities and difficulty integrating into the community.

In this chapter, we focus on mental health problems in children with ASD. We use the term *mental health problem* synonymously with *psychiatric syndrome* and make a distinction with behavior problems. Psychiatric disorders are the syndromes seen in the general population and defined in the *Diagnostic and Statistical Manual of Mental Disorder* (DSM-5; American Psychiatric Association (APA) 2013) such as mood or anxiety disorders, whereas behavior problems are those often seen in children with disabilities such as tantrums or aggression. The relationship between behavior and psychiatric problems is not well understood. Indeed, it is unclear if behavior problems are nonspecific signs of dysregulation or if they are associated with psychiatric disorders in recognizable and predictable ways.

A fundamental conceptual question facing the field is whether or not psychiatric disorders experienced by typically developing children do in fact exist in the same way in the ASD population. In other words, do the core features of ASD alter the clinical presentation of psychiatric syndromes? It is possible that psychiatric disorders observed in typically developing children are the same in ASD. It is also possible that the behavior and emotional problems associated with ASD appear similar to psychiatric syndromes but are really epiphenomena associated with the ASD (i.e., phenocopies). A third possibility is that they are unique syndromes to ASD. This question is at the heart of how we study the phenomena, but will not be resolved here. Regardless of one's position in the debate, there is a growing body of literature indicating that behavioral syndromes in ASD are similar to "conventional" DSM-defined psychiatric syndromes (e.g., Lecavalier et al. 2009, 2011). However, the extent to which ASD and

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developmental delays impact the presentation of psychiatric symptoms is not well studied. In the following sections, we focus on the assessment, prevalence, and intervention of the most commonly observed psychiatric syndromes in children with ASD. Our initial intent was to focus on preschoolers, but we quickly were confronted with the paucity of research in that age group. We therefore broadened our focus to include school age children.

Assessment

Psychiatric Diagnoses

The assessment of mental health problems in children with ASD can be a complex process. Before diving into issues related to assessment, we first take a moment to reflect on the nature of psychiatric diagnoses. Diagnostic categories are attempts to regroup people according to clusters of symptoms or behaviors. A valid diagnosis is one that conveys a large amount of information and facilitates communication among researchers and clinicians. The diagnosis should have some meaning in terms of course and prognosis. In its simplest form, a diagnosis is a probabilistic statement in that not all people in a diagnostic group have the exact same symptoms, course, or prognosis (Angold and Egger 2004). The syndrome represents an alteration of good health that leads to distress and interferes with functioning. In other words, there is a distinction between symptoms and impairment. Finally, psychiatric diagnoses are descriptive, not etiological. In the end, they are needed to reduce complicated dimensional phenomena into dichotomic variables to answer questions such as "*Is this person ill*?" or "*Does this person need treatment?*"

Guidelines for scientifically validating psychiatric syndromes have been proposed (Cantwell 1996; Robins and Guze 1970). Ultimately, the process includes showing that individuals with a specific disorder are unique from individuals who do not have the disorder and different from individuals with other disorders. The variables of greatest interest are those believed to be implicated in some way in the etiology of the syndromes. The first step in the validation process is to reliably define the clinical and associated features. This is much easier said than done as many of the diagnostic boundaries are subjective and the demarcation for pathology is arbitrary. In addition, current classification systems such as the DSM-5 do not specify assessment operations for determining whether a particular child meets criteria for a particular disorder. To make things more complicated, there is widespread comorbidity across disorders (Angold et al. 1999; Gadow et al. 2005).

Given the abovementioned challenges, it is important to keep in mind that our classification systems represent the *current* state of affairs. It represents our best attempt at dividing the universe of mental health conditions into specific categories. As we learn more about disorders, the classification system will change. Through a bootstrapping process, research will change diagnostic categories, which will in turn modify research agendas. In the process, some diagnostic categories will be modified while others will appear or disappear. This process has been illustrated with ASD. While the DSM-IV incorporated a new category on the autism spectrum, Asperger's Disorder, the DSM-5 combined all ASD subtypes into one category (APA 2013).

There are additional diagnostic challenges in early childhood in general and in ASD in particular. Early childhood is marked by many changes in language, cognition, and social and emotional functioning. In addition, contextual factors are more influential in young children than in adults. Because of this, it is sometimes difficult to distinguish normal variations from pathology. In addition, young children cannot contribute the same way as adults to the diagnostic process. The diagnostician must therefore rely more on caregiver report and direct observations. In ASD, social and communicative impairments could make the process even more challenging. Of course, the biggest challenges follow the diagnostic process in that the identification of psychiatric syndromes should lead to available intervention programs and services which are far too scarce in this population.

Conceptualization of Mental Health Problems

One of the fundamental questions with respect to psychiatric syndromes pertains to whether they are best conceptualized as categories or dimensions with varying degrees of severity along a continuum. This is an artificial debate: Psychiatric syndromes are dimensional categories. We use an analogy to illustrate this point. The temperature of water can vary significantly (i.e., a dimensional perspective). In fact, it could get so warm or so cold that it could freeze or evaporate (i.e., change to a different category). These philosophical questions may seem tangential to the topic of assessment but they are not. The conceptualization of behavior and emotional problems has led to contrasting approaches to instrument development and treatment. Below, we present two contrasting views.

With a "top-down" approach, the symptoms that define specific psychiatric disorders are generally determined by the clinical features of expert-diagnosed cases. The preeminent model of this nature is the DSM promulgated by the APA. This "a-priori" model represents a consensus approach between experts. The model defines psychiatric syndromes not only in terms of specific symptoms, but also other prerequisites (e.g., age of onset and duration of symptoms) and exclusion criteria (e.g., presence of co-occurring symptoms or other disorders). It is also necessary to establish that symptoms impair academic, social, or occupational functioning.

A "bottom-up" approach of behavior and emotional problems rests on different premises and methods. A list of behaviors and symptoms of interest for a particular group of individuals is generated. This list is typically generated from patient charts, other instruments, personal experience, or existing definitions of the disorder. Syndromes are then derived with multivariate statistical procedures such as factor analysis. In other words, syndromes are based on the covariation of symptoms or behaviors. In this sense, each instrument is its own taxonomy of behavior and emotional problems. The model is based on symptom severity and impairment is implicit once symptoms are beyond a certain threshold. An objective, but arbitrary cutoff score (e.g., two standard deviations from the normative average) indicates that a person is significantly different from others.

These two approaches are falsely dichotomized. A top-down approach takes empirical studies into consideration and a bottom-up model incorporates subjectivity in the selection of symptoms to be studied. Of course, when a cutoff score is used to identify people with a disorder, a dimensional model becomes categorical.

Impact of IQ on Mental Health Problems

A number of studies have shown that level of functioning moderates psychiatric problems in individuals with ASD. Although there are some exceptions (e.g., Simonoff et al. 2008), studies have generally indicated that a higher IQ is more predictive of symptoms of anxiety and mood problems, whereas a lower IQ is associated with more symptoms of Attention Deficit/Hyperactivity Disorder (ADHD). Below, we briefly summarize select studies reporting on these associations.

Kim et al. (2000) examined symptoms of anxiety and mood problems with a revised version of the parent questionnaire used in the Ontario Child Health Study (OCHS-R), which was based on the *Child Behavior Checklist* (CBCL; Achenbach and Rescorla 2001). In their clinic-based sample of children with autism ($n=40$) or Asperger's syndrome ($n=19$) age 9–14 years old, they found that verbal IQ (VIQ)—nonverbal IQ (NVIQ) discrepancy scores were predictive of anxiety and mood symptoms. Children with lower nonverbal and higher verbal skills were rated as having more anxiety and mood problems.

Brereton et al. (2006) looked at the relationship between IQ and behavioral and emotional problems, as measured by the parent version of the *Developmental Behaviour Checklist* (DBC-P; Einfeld and Tonge 1992), in a clinic-based sample of 381 children and adolescents with autism, ages 3–24 (mean=7.4, SD=3.9). They found that IQ was predictive of symptoms of depression, where children with an IQ in the average range showed more symptoms than children with any level of intellectual disability (ID).

Estes et al. (2007) examined this relationship between IQ and co-occurring behavioral and emotional problems in a longitudinal study of 74 children with ASD. Mental health problems were measured using a variety of parent report questionnaires, including the *Aberrant Behavior Checklist* (ABC; Aman et al. 1985), CBCL, and the short version of the *Conners Parent Rating Scales—Revised* (CPRS-R:S; Conners 1997). The authors found that higher VIQ at age six was predictive of higher ratings of anxiety and depression symptoms at age nine, and lower NVIQ at age six was predictive of higher ratings of ADHD symptoms at age nine.

Using the *Child Symptom Inventory–4* (CSI-4; Gadow and Sprafkin 2002) in a clinic-based sample of 238 children with ASD, ages 6–12 years (mean = 8.6, SD = 1.9), Gadow et al. (2008) reported that higher IQ scores were significantly associated with more parent reported symptoms of Oppositional Defiant Disorder (ODD), Major Depressive Disorder (MDD), Generalized Anxiety Disorder (GAD) and specific phobia. In terms of teacher ratings, lower IQ scores were associated with more symptoms of social phobia and the inattentive subtype of ADHD.

Finally, using the parent version of the *Children's Interview for Psychiatric Symptoms* (P-ChIPS; Weller et al. 1999), a structured interview based on the DSM, Witwer and Lecavalier (2010) evaluated 61 children and adolescents with ASD, ages 6–17 years (mean = 11.2, SD = 3.8). They found that parents of children with an IQ below 70 reported fewer overall psychiatric symptoms than parents of individuals with an IQ greater than 70. Additionally, they found that individuals with an IQ greater than 70 were more likely to meet diagnostic criteria for GAD.

Instrumentation

Caregiver reports are central to the diagnostic process in children with ASD. As such, in this section we briefly review some issues related to standardized instruments used to measure mental health problems in children with ASD. Space constraints preclude a comprehensive review of the literature. We mention a few instruments for illustrative purposes, but we refer the reader to Lecavalier and Gadow (2008) or Boisjoli and Matson (2009) for a more thorough discussion of a number of instruments designed to measure psychopathology in ASD. Our discussion focuses on standardized rating instruments completed by parents, teachers, or clinicians, owing to the fact that much less has been done with self-report, direct observation, or laboratory measures. We define *rating instrument* as a measure with a built-in system for quantifying behaviors or other states. By *standardized*, we mean that the content of the scale, instructions, or scoring system do not change with use. There is a difference between the terms standardized and *normed*, often used incorrectly as synonyms. Developing norms refers to obtaining ratings on a large number of individuals (ideally, representative of a given population). These normative data can be based on different groups, such as community-based or outpatient populations, and serve as a basis for comparing individual scores. A measure can therefore be standardized without having norms. In fact, many standardized instruments used in the ASD literature do not have norms specific to this population.

Regardless of their content or the method underlying their development, rating scales need to be evaluated in terms of their reliability and validity. We refer the reader to articles by Cicchetti (1994) and Meyers and Winters (2002) for a discussion of psychometrics and guidelines for evaluating normed and standardized assessment instruments.

The conceptualization of mental health problems as well as subject characteristics will impact the development and selection of standardized instruments. In addition, there is the question of whether or not scales developed for the typically developing population are appropriate for the ASD population. It is safe to assume that a scale specifically designed for behaviors particular to individuals with ASD or developmental disabilities (DD) might be better suited for use in this patient population. If ASD alter the typical clinical presentation of behavioral syndromes, this population may require a unique set of assessment instruments.

Rating instruments can be grouped according to their scope (global, broadband, narrowband) and structure (empirically-driven or DSM-referenced). By scope, we mean that they can be grouped according to the type and number of behavioral dimensions or syndromes they are designed to evaluate. Global measures such as the *Clinical Global Impressions Scale* (CGI; National Institute of Mental Health 1976) and the *Developmental Disabilities Modification of the Children's Global Assessment Scale* (DD-CGAS; Wagner et al. 2007) provide a single index to evaluate an individual's overall functioning or response to treatment.

Broadband measures contain items assessing a wide range of behaviors and have a number of advantages. First, comorbidity is the rule and not the exception. Second, the subscales of broadband instruments generally share the same metric, and their psychometric properties are based on the same individuals, settings, and informants. Finally, it is generally more cost effective and efficient to administer one broadband measure rather than several different narrowband instruments. Examples of broadband measures used in young children with ASD include the ABC, *Nisonger Child Behavior Rating Form* (NCBRF; Aman et al. 1996), CBCL, DBC, and the *Autism Spectrum Disorder–Comorbid for Children* (ASD-CC; Matson et al. 2009). The CSI-4 is a broadband measure based on the DSM-IV that has been used in several published reports in ASD. It contains subscales representing the most commonly encountered childhood disorders.

More recently, structured interviews based on the DSM, such as the P-ChIPS and the *Kiddie Schedule for Affective Disorders and Schizophrenia, Present and Lifetime Version* (KSADS-PL; Kaufman et al. 1997), have been used in the field (e.g., de Bruin et al. 2007; Gjevik et al. 2011; Leyfer et al. 2006; Simonoff et al. 2008; Witwer et al. 2012). While structured interviews are more time consuming and expensive than caregiver-completed rating scales, they allow clinicians to probe for or clarify information and to evaluate syndrome-specific impairment.

Narrowband measures are those that focus on a specific construct such as anxiety or ADHD and are often times used in the treatment literature. One example of a narrowband measure is the *Children's Yale-Brown Obsessive Compulsive Scale Modified for Pervasive Developmental Disorders* (CYBOCS-PDD; Scahill et al. 2006). This modified version of the CYBOCS was designed to rate the severity of compulsive symptoms in children and adolescents with ASD (items measuring obsessions were excluded). The CYBOCS-PDD is completed within a semi-structured interview by a trained clinician, and scoring is based on the interviewer's judgment. Other narrowband measures that have been used with children with ASD include the *Pediatric Anxiety Rating Scale* (PARS; Research Units on Pediatric Psychopharmacology [RUPP], 2002), *Multidimensional Anxiety Scale for Children* (MASC; March et al. 1997) and *Swanson Nolan and Pelham* (SNAP; Swanson 2012) rating scale for symptoms of ADHD.

Prevalence of Mental Health Problems Commonly Occurring in ASD

Several studies have reported prevalence rates of DSM-defined disorders in children with ASD. In this section, we present some of these studies and discuss select issues related to the different disorders. This is not an exhaustive review of the literature; rather, we selected recently published studies that we considered to be well-designed in terms of diagnostic ascertainment. Rates differ tremendously across studies based on the nature of the samples and the rating instruments used. We note that Simonoff et al. (2008) are the only ones to report on an epidemiological sample. Table 27.1 summarizes the results of these key studies. The following paragraphs briefly describe some of the important features of these studies.

Two of the first studies reporting on DSM-IV disorders in large samples of children with ASD were published by Gadow et al. In the first study, using the *Early Childhood Inventory-4* (ECI-4; Gadow and Sprafkin 1997, 2000), Gadow et al. (2004) reported rates of psychiatric syndromes based on parent and teacher ratings of 172 preschool children aged 3–5 years (mean = 4.2, SD = 0.8), drawn from a DD specialty clinic. Seventy-nine percent of the sample was male. Full-scale IQs (FSIQ) were available for 109 children (63 %) and the average was 79 (SD = 22). In a similar study, Gadow et al. (2005) obtained parent and teacher ratings on a clinic-based sample of 301 children with ASD aged 6–12 years (mean = 8.3, SD = 1.8) with the CSI-4. In addition to being older, this sample also had a higher percentage of males (85 %) and greater intellectual abilities. For those with available FSIQ (*n* = 205; 68 %), the average was 92 (SD = 22).

Leyfer et al. (2006) were amongst the first to report rates of psychiatric disorder based on a structured interview. They reported lifetime prevalence rates, using a modified version of the K-SADS-PL, the *Autism Comorbidity Interview, Present and Lifetime Version* (ACI-PL). Their sample consisted of 109 community-recruited children with autism who were participating in other studies at the two research sites in Boston and Salt Lake City. The children were 5–17 years old (mean = 9.2, SD = 2.7) and the sample was primarily males (94 %). Information on intellectual functioning was available for 96 individuals (88 %), with a mean FSIQ of 83 (SD = 23).

de Bruin et al. (2007) investigated comorbid psychiatric disorders in 94 children who were consecutive referrals that met research-criteria for Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) at an outpatient clinic in the Netherlands. Parents were interviewed with the Dutch version of the *Diagnostic Interview Schedule for Children, Version IV* (DISC-IV; Shaffer et al. 1998), and also rated their child on the *Children's Social Behavior Questionnaire* (CSBQ; Luteijn et al. 1998). Eighty-eight percent of the children were male and their age ranged from 6–12 years (mean = 8.5, SD = 1.9). IQs were available for 90 children (96 %), with a mean of 91 (SD = 17; range = 55–120).

Simonoff et al. (2008) reported weighted prevalence estimates based on a stratified random sampling procedure. They reported 3-month point prevalence rates of psychiatric comorbidities among an epidemiological sample of 112 children with ASD. IQ information was available for all children, with a mean FSIQ of 73 (SD = 22; range 19–124). Children were 10–14 years of age (mean = 11.5) and 88 % were male. Psychiatric comorbidities were assessed with a structured interview with parents, the *Child and Adolescent Psychiatric Assessment* (CAPA; Angold and Costello 2000).

Finally, two studies assessed psychiatric functioning with the K-SADS-PL. Mattila et al. (2010) assessed 50 high functioning children with ASD (FSIQ > 75). Participants were recruited from community (*n* = 18) and clinic (*n* = 32) resources. Both parents and children were interviewed in this study. Both current and lifetime diagnoses of comorbid psychiatric disorders were made by trained clinicians on the basis of information provided by both parents and children. Children were 9–16 years old (mean = 12.7, SD = 1.5) and 76 % were male. Gjevik et al. (2011) assessed 71 children and adolescents aged 6–16 years (mean = 11.8, SD = 3.3) who were attending a special school for ASD. They completed the K-SADS-PL with parents, reporting current diagnoses only. The sample was composed primarily of boys (82 %), most of whom functioned in the range of ID (mean NVIQ = 65, SD = 30).

Anxiety Disorders

The DSM-IV-TR cautioned against diagnosing anxiety disorders in individuals with ASD, including GAD, social anxiety, and separation anxiety (APA 2000). The DSM-5 criteria cautions against diagnosing separation anxiety and social anxiety as well and additionally extend this caution to obsessive-compulsive disorder (OCD; APA 2013). Despite this, anxiety disorders are some of the most commonly co-occurring psychiatric disorders in individuals with ASD, with up to half of children meeting criteria for any anxiety disorder according to parent ratings, and many children meeting diagnostic criteria for multiple anxiety disorders. In fact, children and adolescents with ASD show higher levels of anxiety than typically developing controls (for a review, see MacNeil et al. 2009).

Despite the high rate of co-occurring anxiety disorders in individuals with ASD, anxiety may often be unrecognized or mislabeled. There is considerable overlap between the symptoms of ASD and those of anxiety. Behaviors commonly associated with ASD such as verbal rituals and repetitive questioning can also be interpreted as symptoms of anxiety. Core deficits of ASD, including communication deficits and difficulties in emotion recognition and labeling, complicate diagnosis even further as many children with ASD are unable to recognize or report symptoms of anxiety.

Considerable debate has arisen regarding the relationship between OCD and ASD as repetitive and ritualistic behaviors are core symptoms of both disorders. One distinction between disorders is that repetitive behaviors associated with ASD do not seem to occur against the person's will, in contrast to OCD where compulsions are uncontrollable and unpleasant. In a comparison of repetitive behavior in typically developing children, high functioning autism (HFA), or OCD, Zandt et al. (2009) found that children with OCD exhibited more routines and rituals as well as more compulsions and obsessions than children with ASD. In addition, the obsessions and compulsions were more sophisticated in children with OCD. Matson and Nebel-Schwalm (2007) suggested the following when diagnosing OCD in ASD. First, the individual with ASD should engage in behaviors that are typical of OCD, such as frequent hand washing to kill germs. Second, the OCD symptoms exhibited should be greater than the repetitive behaviors expected in a typical case of ASD. Lastly, individuals with ASD and comorbid OCD should show reduction in OCD symptoms from interventions known to be effective for OCD.

Mood Disorders

Depression Depression can occur in individuals with ASD, but typically does not develop until after puberty. As can be seen in Table 27.1, rates of MDD and dysthymic disorder have ranged from 1–11 %. In their epidemiological sample, Simonoff et al. (2008) found that 0.9 % met criteria for MDD and 0.5 % for dysthymic disorder. However, a further 11 % of the sample had a significant period of depression or irritability, but did not fully meet DSM-IV criteria for MDD or dysthymic disorder.

Rates of depression seem higher in individuals with ASD compared to community control groups of typically developing children. For instance, Gadow et al. (2005) found that 6 and 11 % of their sample of 6- to 12-year-olds with ASD screened positively for MDD and dysthymic disorder, respectively. In contrast, no typically-developing children in regular education screened positively for MDD and less than 1 % did for dysthymic disorder. Some studies have shown much higher rates in both individuals with ASD and typically developing control groups. For example, Mayes et al. (2011) assessed children ages 6–16 with the *Pediatric Behavior Scale*, and found that 54 % of children with HFA (IQ greater than 80) and 42 % of lower functioning children with ASD (IQ less than 80) were depressed. In contrast, 19 % of typically developing children in their sample were depressed.

Similar to difficulties associated with diagnosing anxiety, communication deficits and difficulties understanding emotions can make diagnosis of depression challenging in individuals with ASD. As a result, many of the symptoms of depression are reported by caregivers or observed in changes in the child's behavior (Ghaziuddin et al. 2002; Stewart et al. 2006). Some case studies have reported that the onset of depression can be associated with the onset or exacerbation of problem behaviors, including self-injury and aggression, as well as a decrease in self-care behaviors, such as toileting (e.g. Clarke et al. 1999; Long et al. 2000).

Bipolar spectrum disorders Bipolar disorder appears to be less common in individuals with ASD. Leyfer et al. (2006) found low lifetime prevalence rates of 1.9 % for Bipolar I disorder, 0.9 % for Bipolar II disorder, and 0.9 % for cyclothymia. Similarly, de Bruin et al. (2007) found that 3.2% of their sample reported a manic episode and 3.2% reported a hypomanic episode in the previous year. Gjevik et al. (2011) on the other hand reported that no children currently met diagnostic criteria for a manic episode or bipolar disorder.

Similar to depression and anxiety, the diagnosis of bipolar disorder can be challenging in individuals with ASD. Additionally, the diagnosis of childhood bipolar disorder is a controversial topic due to the dramatic increase in diagnostic rates and unclear diagnostic criteria for this age group (Leibenluft and Rich 2008). However, clinicians should take note of any cyclical changes in activity, behavior, or interests in children with ASD, as well as a family history of bipolar disorder as this may indicate comorbid bipolar disorder.

Disruptive Behavior Disorders

Attention deficit/hyperactivity disorder According to the DSM-IV-TR, ADHD should not have been diagnosed if symptoms occurred solely in the course of ASD (APA 2000). However, the new criteria for the DSM-5 (APA 2013) removed this stipulation because there is currently no evidence that ADHD is universally associated with ASD. Furthermore, ADHD symptoms in individuals with ASD respond to similar treatments as those used in individuals without ASD.

In a recent review of research on the comorbidity of ADHD and ASD, Gargaro et al. (2011) concluded that while more neuropsychological research is needed to fully understand the comorbid presentation of ASD and ADHD, current clinical opinion, research, and theoretical models suggest that these disorders are distinct, and that their comorbidity is frequent. In one study looking at the comorbidity of these disorders, Gadow et al. (2006) examined differences in associated features in two groups of children: one group with both ASD and ADHD and one with ASD only. Results indicated that children with both ASD and ADHD were significantly different from children with ASD only in terms of co-occurring psychiatric symptoms, ASD symptoms, as well as other psychosocial variables, suggesting that children with both ASD and ADHD are distinct from children with ASD only.

As seen in Table 27.1 and elsewhere (e.g., Kim et al. 2000; Sinzig et al. 2009), the prevalence of ADHD in individuals with ASD is quite high. These rates are significantly higher than what is seen in typically developing children. For example, Gadow et al. (2004) found that 41% of preschool children with ASD screened positive for ADHD, compared to 6% of typically developing children. This discrepancy was even larger with school aged children, where 60% of children with ASD screened positive for ADHD compared to 6% of typically developing children.

Little is known about the causes of the high comorbidity of ADHD and ASD. However, genetic studies are pointing at the possibility of a common genetic basis for the two disorders. Linkage studies have shown that similar areas of the genome may be involved in both ASD and ADHD, including 5p13, 9q33–34, 16p13, and 17p11–q11. However, it is unclear if these overlapping regions reflect common risk genes or only genes that are in close proximity to each other (Smalley et al. 2004). In a community-based sample of 6,771 twins, there were significant correlations (0.54 for parent data; 0.51 for teacher data) between autistic and ADHD traits, as measured by the *Childhood Asperger Syndrome Test* and the *Conners' Revised Parent/Teacher Rating Scales*, suggesting a genetic overlap between the two disorders (Ronald et al. 2008). In another population-based twin sample, ADHD was associated with elevated rates of ASD traits as measured by the *Missouri Assessment of Genetics Interview for Children*, a semi-structured interview based on the DSM-IV, and the *Social Responsiveness Scale*, further suggesting a genetic overlap between ADHD and ASD (Reiersen et al. 2007).

Oppositional defiant disorder Many children with ASD additionally exhibit symptoms of ODD, characterized by hostile and defiant behavior toward parents and other adults. As can be seen in Table 27.1, rates vary tremendously across studies, ranging from 4 to 37%. Rates of

Table 27.1 Prevalence rates of parent-reported psychiatric syndromes in children with ASD

	Gadow et al. 2004[a]	Gadow et al. 2005[a]	Leyfer et al. 2006[b]	de Bruin et al. 2007	Simonoff et al. 2008[b]	Mattila et al. 2010[c]	Gjevik et al. 2011
Sample	172 with ASD; 3–5 years old	284 with ASD; 6–12 years old	109 with autism; 5–17years old	94 with PDD-NOS; 5–12-years old	112 with ASD; 10–14 years old	50 with AS or HFA; 9–16 years old	71 with ASD; 6–18 years old
Measure used	ECI-4 (%)	CSI-4 (%)	ACI-PL (%)	DISC-IV-P (%)	CAPA (%)	K-SADS-PL (%)	K-SADS-PL (%)
Any comorbid psychiatric disorder	–	–	72	80.9	70.8	74	72
Any anxiety disorder	–	–	–	55.3	41.9	42	42
Separation anxiety disorder	5.9	6.8	11.9	8.5	0.5	2	0
Panic disorder	–	–	0	1.1	10.1	2	–
Agoraphobia	–	–	–	6.4	7.9	2	–
Social phobia	10.2	–	7.5	11.7	29.2	4	7
Specific phobia	17.9	–	44.3	38.3	8.5	28	31
Obsessive-compulsive disorder	–	–	37.2	6.4	8.2	22	10
Generalized anxiety disorder	5.1	24.3	2.4	5.3	13.4	–	0
Any mood disorder	–	–	–	13.8	1.4	6	10
Major depressive disorder	–	5.6	10.1	10.6	0.9	6	1
Dysthymic disorder	–	11.3	–	2.1	0.5	–	1
Bipolar disorder	–	–	2.8	–	–	–	0
Any disruptive behavior disorder	–	–	–	61.7	–	44	–
Any form of attention-deficit/hyperactivity disorder	41.4	60.3	30.6	44.7	28.2	38	31
Predominantly inattentive	19.5	35.5	20.0	14.9	–	12	21

Table 27.1 (continued)

	Gadow et al. 2004[a]	Gadow et al. 2005[a]	Leyfer et al. 2006[b]	de Bruin et al. 2007	Simonoff et al. 2008[b]	Mattila et al. 2010[c]	Gjevik et al. 2011
Sample	172 with ASD; 3–5 years old	284 with ASD; 6–12 years old	109 with autism; 5–17years old	94 with PDD-NOS; 5–12-years old	112 with ASD; 10–14 years old	50 with AS or HFA; 9–16 years old	71 with ASD; 6–18 years old
Measure used	ECI-4 (%)	CSI-4 (%)	ACI-PL (%)	DISC-IV-P (%)	CAPA (%)	K-SADS-PL (%)	K-SADS-PL (%)
Predominantly hyperactive	9.5	5.3	3.5	8.5	–	0	6
combined	12.4	19.5	7.0	21.3	–	26	4
Oppositional defiant disorder	13.5	27.6	7.0	37.2	28.1	16	4
Conduct disorder	1.5	7.1	–	9.6	3.2	2	3

ASD autism spectrum disorder; *PDD-NOS*: pervasive developmental disorder not otherwise specified; *AS* Asperger's Syndrome; *HFA* high-functioning autism; *ECI-4* Early Childhood Inventory–4; *CSI-4* Childhood Symptom Inventory–4; *ACI-PL* Autism Comorbidity Interview, Present and Lifetime Version; *DISC-IV-P* Diagnostic Interview Schedule for Children, Version IV; *CAPA* Child and Adolescent Psychiatric Assessment; *K-SADS-PL* Kiddie Schedule for Affective Disorders and Schizophrenia, Present and Lifetime Version.–indicates that the prevalence rate was not reported

[a] In Gadow et al. 2004, 2005, prevalence rates were originally published by gender; combined prevalence rates were calculated using the published data

[b] While all other studies published current prevalence rates, Leyfer et al. 2006 reported lifetime prevalence rates and Simonoff et al. 2008 published 3-month prevalence rates

[c] Whereas prevalence rates for all other studies are on the basis of parent report, diagnoses in Mattila et al. 2010 were made on the basis of K-SADS-PL completed with both parent and child. Additionally, all rates presented for Mattila et al. 2010 are for current prevalence of these disorders, although the authors also published lifetime prevalence rates

ODD appear to be higher in children with ASD than typically developing children. For example, Gadow et al. (2004) found that 13 % of preschoolers with ASD positively screened for ODD, compared to 7 % of regular education students. In their sample of 6–12 year olds, Gadow et al. (2005) found an even larger discrepancy, with 28 % of children with ASD positively screening for ODD, compared to 4 % of regular education children.

In both typically developing children and those with ASD, disruptive behavior disorders such as ODD and conduct disorder (CD) frequently co-occur with ADHD. Simonoff et al. (2008) found that 52 % of those with ASD and ADHD also met criteria for either ODD or CD. Gadow et al. (2008) compared four groups of children: ASD and ODD ($n = 19$), ASD and ADHD ($n = 207$), ASD and both ODD and ADHD ($n = 113$), and ASD only ($n = 235$). Results indicated that children with ASD and no ODD are distinct from children with ASD and ODD. Those without comorbid ODD showed less severe symptoms of GAD and MDD. Additionally, children with ASD and both ODD and ADHD showed more severe symptoms of CD, MDD, dysthymia, obsessions, compulsions, and separation anxiety disorder, as well as more severe social deficits and perseverative behaviors than children with ASD only.

Conduct disorder As seen in Table 27.1, prevalence rates of CD in children with ASD range from 1.5 to 10 %. There has been relatively little research on the comorbidity of CD in children with ASD, which may be due to the fact that social, communication, and intellectual difficulties associated with ASD make it difficult to establish whether the individual engages in aggressive behaviors with the intent to do harm to another person. Intent to harm other people is a critical piece of the CD diagnosis.

Tic Disorders

Tics are sudden vocalizations or motor movements that are recurrent and stereotyped (APA 2000). At times, they can be quite difficult to differentiate from stereotyped behaviors and other repetitive behaviors that occur as part of ASD. However, tics are typically short in duration, inappropriate for the context, and often disrupt behavior and speech (Baron-Cohen et al. 1999). Few studies have looked at the prevalence of tics in children with ASD. However, available evidence seems to suggest that tic disorders occur in a number of children with ASD. For instance, Gjevik et al. (2011) found that 11 % of their sample met criteria for any tic disorder, while Mattila et al. (2010) found a rate of 26 %. Specific estimates of motor tics range from 6 to 17 % (Gadow et al. 2004; Mattila et al. 2010), and from 6 to 13 % for verbal tics (Gadow et al. 2004; Mattila et al. 2010). When looking specifically at Tourette's Disorder, characterized by the presence of both motor and verbal tics, prevalence rates vary from 6.5 to 14 % in clinic-based samples of children with ASD (Baron-Cohen et al. 1999; Mattila et al. 2010). In their population-based sample of children with ASD, Simonoff et al. (2008) found a slightly lower prevalence rate of 4.8 %.

Rates of verbal and motor tics appear to be higher in children with ASD compared to typically developing children. For example, Gadow et al. (2005) reported that 17 % of clinic-referred preschool children with ASD had motor tics, compared to 1 % of typically developing children. Similarly, 14 % of clinic-referred school aged children with ASD showed verbal tics, compared to 2 % of typically developing children (Gadow et al. 2004). The presence of tics in children with ASD appears to be related to the presence of more severe symptoms of other psychiatric disorders, with the combination of ADHD and tics predicting the most severe symptoms of other psychiatric disorders, including ODD, CD, MDD, dysthymia, GAD, separation anxiety disorder and OCD (Gadow and DeVincent 2005).

Schizophrenia

Historically, autism was thought to be a form of schizophrenia. It is now clear that these two conditions are distinct disorders, although they can occur together. These two disorders can be differentiated in a number of ways. Whereas autism has its onset in early childhood, schizophrenia typically does not appear until adolescence or early adulthood. Additionally, individuals with schizophrenia typically report hallucinations and delusions, which are not common symptoms associated with ASD. Family psychiatric history also differs between the two disorders as individuals with schizophrenia are more likely to have relatives diagnosed with schizophrenia spectrum disorders and individuals with ASD are more likely to have a family history of ASD. Additionally, ASD is often associated with ID and epilepsy, which is not typical in schizophrenia. Lastly, ASD is most often a chronic condition, whereas schizophrenia, while chronic, can also include periods of complete recovery. Despite these differences, autism and schizophrenia share some features and associated deficits. Both are characterized with social and language difficulties and inappropriate or constricted affect. Additionally, both autism and schizophrenia can be conceptualized as including deficits of theory of mind and mirror neuron deficits (King and Lord 2010).

Evidence points to a genetic overlap in ASD and schizophrenia. As both disorders occur in roughly 1 % of the population, the co-occurrence of schizophrenia and ASD should be quite rare at 0.01 %. Although research is currently limited, up to 10 % of individuals with ASD receive a diagnosis of a schizophrenia spectrum disorder (Howlin 2000), and 28 to 55 % of individuals with childhood-onset schizophrenia meet diagnostic criteria for ASD (Rapoport et al. 2009). Additionally, parental schizophrenia is a risk factor for ASD, further pointing to a genetic overlap between the two disorders (Daniels et al. 2008; Larsson et al. 2005). Candidate gene, linkage, and expression studies of schizophrenia and autism have shown several regions that are associated with both disorders, including 1q21.1, 1q42, 2p16.3, 2q31.1, 7q22.1, 7q35–q36.1, 15q11–q13, 15q25, 16p11.2, 16p12.1, 17p12, 22q11.21, and 22q13.3 (for reviews, see Burbach and van der Zwaag 2009; King and Lord 2010; Rapoport et al. 2009). Lastly, similar pharmacologic treatments are indicated for both disorders as the only two drugs approved for behavioral problems associated with autism are risperidone and aripiprazole, which were originally developed for schizophrenia.

Interventions

Intervention research for comorbid psychiatric disorders in ASD is riddled by the difficulty in making an accurate diagnosis, as discussed above. Several interventions have been developed that target behavioral syndromes, which may or may not be diagnosable psychiatric syndromes. Approaches to treatment have focused primarily on behaviorally-based, cognitive-behavioral, or psychopharmacological interventions. In the following section, we summarize select studies in each of these areas.

Behavioral-Based Interventions

Parent training (PT) Among typically-developing children, disruptive behavior disorders, such as ADHD, ODD, and CD, are often targeted with parent-implemented interventions, especially at younger ages. The premise behind PT is that parents can learn the skills necessary to modify their child's environment in ways that would improve behavior. PT may occur alone, or in conjunction with medication, such as in the Multimodal Treatment study of ADHD (MTA), where combined treatment improved some outcomes beyond that achieved by either treatment alone (MTA Cooperative Group 1999).

Several PT programs have been adapted for use among those with DD, including ASD. For example, Roberts et al. (2006) used the 10-week *Stepping Stones Triple P* (SSTP; Sanders et al. 2003) program among children with DD. SSTP can be individually-administered or group-administered. It utilizes video modeling of parenting skills, rehearsal, and didactics. Using a randomized controlled trial (RCT), Roberts et al. assigned 50 children between 2 and 7 years of age with various DD to intervention ($n=27$) or wait-list control ($n=23$). Although none of the children were reported to have comorbid psychiatric diagnoses, all exhibited behavior problems such as noncompliance and oppositional behavior, which the program directly targets. Children whose parents received the intervention were rated by their mothers at the end of treatment as exhibiting less total problem behaviors and were observed as being less noncompliant and oppositional.

Whittingham et al. (2009) extended the research on SSTP to a larger sample of children, all of whom were diagnosed with ASD. Comic strip conversations and social stories were added to SSTP in order to improve children's understanding of certain skills. The researchers randomized 59 children with a mean age of 5.9 years to intervention ($n=29$) or waitlist-control ($n=30$). Didactic lessons were given in group format, but practice and feedback sessions were provided to families individually. Results suggested that families receiving SSTP showed improved parenting skills and decreases in the frequency and disruptiveness of child problem behaviors. Follow-up information at 6 months was available for 26 of the 29 families. Treatment gains were maintained for all 26 families, with problem behaviors and parenting skills no longer in the clinical range.

McIntyre (2008) conducted a RCT of a modified version of the *Incredible Years Toddler Program* for children 2–5 years old with a DD. Twenty-four children were randomized to treatment and 25 were randomized to a waitlist-control condition. No children had a diagnosed disruptive behavior disorder, though all were viewed at high risk for developing one. Half ($n=12$) of the treatment group had ASD, but they did not differ in treatment response from those with other DDs. The treatment was found effective at reducing dysfunctional parenting during a home-based observation and at reducing child behavior problems on parent-completed rating forms.

Parent-Child Interaction Therapy (PCIT; Hembree-Kigin and McNeil 1995) has also been adapted for use among those with ASD. PCIT is composed of two phases: Child Directed Interaction (CDI), during which parents are taught to follow a child's lead, basic reinforcement principles, and appropriate use of ignoring; and Parent Directed Interaction (PDI), during which parents are taught how to give appropriate commands to their child, reinforce compliance, and use timeout. PCIT is not set around a structured number of sessions but rather on mastery of skills in each phase. In one study, PCIT was modified for ASD to include use of redirection during the CDI, prohibiting play related to excessive interests, and higher frequency of praise for appropriate social interactions (Solomon et al. 2008). Nineteen boys with HFA between the ages of 5 and 12 years old were randomized to immediate treatment ($n=10$) or waitlist control ($n=9$). For this study, the authors limited each phase (CDI and PDI) to 6 weeks. At the end of the trial, PCIT reduced parent-rated behavior problems and increased parent-rated adaptability.

Some PT programs have been specifically developed for those with ASD. Johnson et al. (2007) developed a manualized PT program based on the principles of Applied Behavior Analysis (ABA). The package consisted of 11 core sessions, up to 3 optional sessions, and up to 3 booster sessions. Sessions lasted 60–90 min and were delivered individually to families. The content of the core sessions included preventive approaches and schedules, use of reinforcement, compliance training, functional communication training and the teaching of other adaptive skills. Content of optional sessions included addressing toileting difficulties, time-out, or token economy systems. Sessions used direct instruction, video vignettes, practice activities, and role playing. In addition, families were given individualized homework between sessions. In the initial pilot study, the program significantly reduced child noncompliance and irritability on the ABC and increased adaptive skills in a group of 17 children between 4 and 13 years of age (mean = 7.7). The program was then used in a multi-site RCT comparing risperidone alone to risperidone and PT in 124 children aged 4 to 13 years (Aman et al. 2009). Results indicated that the combined treatment group had significantly lower parent-rated noncompliance ($d=0.34$), ABC-irritability ($d=0.48$), and ABC-hyperactivity/noncompliance ($d=0.55$) scores than the medicine only group at the week 24 endpoint. In addition, final mean risperidone dose was significantly lower in the combined treatment group. The advantages seen for combined treatment among those with ASD were greater than that observed in the MTA study (MTA Cooperative Group 1999), suggesting that a combination of treatments may provide meaningful reductions in problem behaviors beyond what medication can offer alone.

Behavior therapy Graduated exposure, response prevention, and reinforcement are widely used in clinical settings in the treatment of ASD with comorbid specific phobias or OCD (Hagopian and Jennett 2008). Graduated exposure with response prevention involves creating a hierarchy of feared stimuli. The child is systematically presented with a feared stimulus and an escape or other maladaptive coping response is prevented. This process is repeated with increasingly more feared stimulus until a fear response is extinguished to all stimuli on the hierarchy. Approach responses at all steps of the hierarchy are reinforced. For children with difficulty initiating an approach response, video or in vivo modeling may serve as a prompt.

Despite their widespread use in clinical settings, there are surprisingly few published reports on behavior therapy to reduce anxiety in children with ASD. In one study, Matson (1981) successfully treated three girls with ASD between 8 and 10 years of age for their social fears. Parents used in vivo modeling, prompted an approach response, and provided social praise. Prompts were faded and treatment gains were maintained for 6 months. Using a similar procedure, Love et al. (1990) successfully treated specific phobias in two boys, aged 4 and 6 years. Parents promoted an approach response by first modeling it, then by physically and verbally prompting it. Positive reinforcement was provided contingent on successful exposure and approach to feared stimuli. Prompts were faded and treatment gains were maintained for the children at a 1-year follow-up.

Exposure may also be effective without the response prevention component. Ricciardi et al. (2006) successfully treated the specific phobia of an 8-year-old boy with ASD using only exposure and reinforcement for an approach response. In order to encourage the approach response, preferred toys were used as distractor objects placed near the feared stimulus in order to provide more natural reinforcement. Escape was not prevented, though the child rarely left the treatment session. The child was able to approach the feared object after intervention, but maintenance of treatment gains was not reported.

Restricted and repetitive behaviors (RRB) have also been targeted using behavioral therapy. One study targeted insistence on sameness in five preschoolers with ASD aged between 39 and 65 months (Boyd et al. 2011). The therapist trained the parents to implement response interruption, redirection, and use reinforcement. Both the parents and therapists conducted the intervention directly with the child in the clinic setting, and parents were expected to continue treatment in the home. The end of the intervention was marked by reduced insistence on sameness and increases in other appropriate behaviors. Gains were maintained for 2–4 weeks after intervention.

Of note, Boyd et al. (2011) targeted RRB considered by the researchers to be core ASD symptoms, rather than symptoms of a comorbid anxiety disorder. Although behavior therapy may be beneficial in the treatment of OCD, at this writing no trials of behavior therapy for OCD in ASD were identified. Both diagnoses may be beneficial, as response to treatment may vary depending on the nature of the RRB (ASD or OCD symptom).

Cognitive behavioral therapy A sizeable proportion of research for comorbid conditions in ASD has focused on cognitive behavioral therapy (CBT), which includes a behavioral component and cognitive restructuring exercises. Anger, which may be a symptom of a disruptive behavior disorder, has been successfully treated with CBT. Sofronoff et al. (2007) randomized 45 children ages 10–14 years with HFA to immediate ($n=24$) or delayed ($n=21$) treatment for anger management. The 6-week CBT program focused on discussing emotions and creating a “toolbox” to fix problem emotions. The treatment reduced instances of aggression and increased problem-solving skills after intervention, which were maintained for 6 months.

Although systematic evaluations of CBT for the treatment of depression in ASD are lacking, many authors recommend its use. Most of the CBT research in ASD has focused on anxiety. Reviews have generally supported the effectiveness of CBT for comorbid anxiety among those with HFA (e.g. Lang et al. 2010; Moree and Davis 2010). Initial case studies of CBT (e.g. Greig and MacKay 2005; Sze and Wood 2007, 2008) focused on preadolescents with anxiety and HFA and were generally supportive of its positive effects. For instance, following an intensive CBT program (i.e., up to 13 individual sessions, 5 concurrent group sessions, and parent involvement over 11 weeks), three of four adolescents with HFA showed statistically significant reductions in anxiety and increases in social skills (White et al. 2009). In another study, ten children with HFA and anxiety between 8 and 14 years of age showed improvement on parent-rated (but not child-rated) symptoms of anxiety after a 12-week CBT program when compared to 23 children in a waitlist control group (Reaven et al. 2009). This program involved time within each session for large-groups that combined parents and children, separate parent- and child-groups, and parent-child dyads.

At the time of this writing, three large-scale trials in support of the effectiveness of CBT for comorbid anxiety have been published. Sofronoff et al. (2005) randomized 71 children between 10 and 12 years old with HFA and anxiety to one of three groups: a child-only treatment group ($n=23$), a combined parent and child treatment group ($n=25$), or a waitlist control group ($n=23$). The treatment groups both received six two-hour sessions of group therapy. The intervention focused on recognizing emotions, recognizing the physical changes that accompany anxiety, and creating a "tool box" to fix anxiety-provoking situations. Both treatment groups showed reductions in anxiety symptoms and increases in problem solving skills compared to the waitlist control group, but the combined treatment was more effective overall and continued to show improvement at the 6-week follow-up.

Chalfant et al. (2007) modified the *Cool Kids* program for children with HFA and randomly assigned 47 children between 8 and 13 years old to immediate treatment ($n=28$) or waitlist control ($n=19$). The modified program involved nine weekly sessions and three monthly follow-up sessions utilizing exposure, role-playing, anxious-response recognition, and simplified cognitive restructuring exercises. Those who received immediate treatment showed reductions in both child- and parent-reported anxiety symptoms. Additionally, 20 children no longer met diagnostic criteria for any anxiety disorder following treatment.

Finally, Wood et al. (2009) conducted a RCT of a modified version of the *Building Confidence* program. They randomized 40 children with HFA and comorbid anxiety between 7 and 11 years of age to either immediate ($n=17$) or waitlist ($n=23$) conditions. The program lasted 16 weeks and included training on coping skills, in vivo graded exposure, and parent training to teach how to create exposure experiences for their child, use positive reinforcement, and promote child independence. The program was modified to target social skill deficits, adaptive skill deficits, RRB, and additional comorbid disruptive behavior disorders. A comprehensive reinforcement system was developed across all skills. Results indicated statistically significant reductions in parent-rated but not child-rated anxiety on the MASC. Additionally, 9 of 17 children in the immediate treatment group no longer met criteria for an anxiety disorder following treatment, though one relapsed within 3 months. Other treatment gains were maintained at the 3-month follow-up.

Many protocols addressed core ASD social deficits in addition to the anxiety (e.g., by teaching theory of mind or social skills). The most common modifications from traditional CBT programs for those with HFA involve reducing cognitive aspects of treatment and adding more behavioral strategies, such as differential reinforcement, visual strategies, and clearer prompting of behaviors (Lang et al. 2010; Moree and Davis 2010). It is also recommended that parents be actively involved in the therapy, encouraging exposure and using reinforcement outside of therapy sessions.

Sturmey (2004, 2005) has questioned the effectiveness of CBT among those with ID. Because these individuals often lack the social cognition necessary for cognitive therapy, he proposed that treatment responses may be due to the behavioral aspects of the therapy. Deficits in social cognition are core diagnostic criteria for ASD such that the same reflection can be made for CBT among those with ASD. In their review, Lang et al. (2010) argued that a component analysis of the comprehensive treatment packages is necessary to determine if the cognitive aspects make any meaningful changes beyond the behavioral interventions. Only two studies attempted to measure changes in cognitions (Sofronoff et al. 2005, 2007). In both cases, they found that the ability to come up with multiple novel solutions to a problem situation increased after intervention. In the other studies, it is unclear what, if any, cognitive changes occurred after CBT.

Even though deficits in social cognition are part of ASD, some individuals may have the skills necessary to participate in CBT. Lickel et al. (2012) compared 40 children with ASD to 40 children without ASD (age range = 7–12 years) on prerequisite cognitive skills for CBT, specifically emotion recognition, cognitive mediation, and discrimination between thoughts, feelings, and behaviors. All children had a NVIQ or VIQ at or above 85 and the language skills necessary to complete Module 3 on the *Autism Diagnostic Observation Schedule*. The children with HFA performed more poorly than typically developing children on all tasks. However, after controlling for differences in VIQ, only the ability to recognize emotions differed between groups. Lickel et al. (2012) interpreted this as supporting the ability of children with HFA to participate in CBT. However, one could argue that parceling out differences on VIQ removes meaningful differences between children with and without ASD. It seems as though some individuals with HFA may have the skills necessary for CBT, but these are likely not as well-developed as among typically-developing children.

Psychopharmacological Treatments

There are currently no medications to treat the core symptoms of ASD. Rather, psychotropic medications are typically used for behavioral stabilization. It is important to keep in mind that drug therapies are typically palliatives in that they do not alter underlying pathophysiology in such a way as to cure the behavioral disturbance. Most of the time, drug discontinuation is associated with some degree of behavioral deterioration in the absence of alternative compensatory interventions.

A number of studies have examined the prevalence of use of psychotropic medicines in people with ASD (e.g., Aman et al. 1995, 2003; Langworthy-Lam et al. 2002; Witwer and Lecavalier 2005). Aman et al. (2005) analyzed data from their three previous surveys in North Carolina and Ohio and found that the prevalence of use of any psychotropic medication increased significantly with time to about 45 %. Significant increases in use over time were noted for antipsychotics, antidepressants, psychostimulants, and antihypertensives. Across the three studies the following variables were consistently associated with greater likelihood of medication use: greater age, more severe symptoms of autism and ID, and more restrictive educational placement. Similarly, Witwer and Lecavalier (2005) examined the 1-year treatment rates and patterns of 353 children with ASD (mean age of 10 years) attending public schools across Ohio. In this survey, parents also completed measures of social competence, problem behavior, and adaptive behavior. Results indicated that 47 % of children were administered at least one psychotropic medication in the past year. In addition, 17 % received some type of specially formulated vitamin or supplement; 16 % were on a modified diet; 12 % were taking some combination of psychotropic medication and an alternative treatment; and 5 % were prescribed an antiepileptic. The vitamin and supplement usage was associated with younger age and higher parental education. As reported in the Aman studies, greater age and lower adaptive skills were associated with higher levels of psychotropic medication use.

"Irritability" has been the object of several pharmacological trials in ASD. The term is used to describe the behaviors found on the Irritability subscale of the ABC, including self-injury, screaming, and tantrums. After several open-label and large multi-site trials (Marcus et al. 2009; McCracken et al. 2002), the Food and Drug Administration (FDA) has approved aripiprazole and risperidone for the treatment of irritability associated with ASD. Risperidone may even improve some, but not all, core-ASD symptoms (McDougle et al. 2005). In the RUPP study of risperdone (McCracken et al. 2002), 69 % of children were considered responders. Marcus et al. (2009) found that 55 % of children responded to aripiprazole at the lowest fixed dose. Although more research is needed, it seems as though aripiprazole has more preferential pharmacological properties than risperidone (Farmer and Aman 2011).

Psychostimulants, antipsychotics, Selective Serotonin Reuptake Inhibitors (SSRI), opiate blockers, and other drug classes have all been used to treat hyperactive symptoms of ADHD, but few studies have evaluated the effect on inattentive symptoms (Aman and Langworthy 2000). Most studies have lacked strong methodologies to evaluate the effectiveness of medications to treat ADHD (c.f. Siegel and Beaulieu 2012). Psychostimulants have shown the greatest promise in ameliorating hyperactivity. However, compared to their typically developing counterparts with ADHD, children with ASD are more likely to experience adverse events, and fewer will be considered responders. For example, in the RUPP (2005) evaluation of methylphenidate in children with ASD and ADHD, only 49 % were considered responders, and 18 % of participants exited the trial early due to adverse events. This is significantly different than what occurred in the MTA study with typically developing children with ADHD, where 69 % were considered responders and less than 2 % discontinued due to adverse events. Thus, higher rates of use for non-stimulant ADHD medications, such as selective norepinephrine reuptake inhibitors, α-agonists or β-blockers are seen in children with ASD.

There have been no well-controlled drug trials for mood or anxiety disorders. Among typically developing children, SSRI are frequently prescribed for mood and anxiety disorders (though the FDA has placed a black-box warning on SSRI use in children and adolescents due to increased risk of suicidality). Among children with ASD, trials of SSRI failed to find support as a treatment for the core ASD symptoms of RRB, and have not been evaluated for the treatment of psychiatric comorbidity, including anxiety and depression (for a comprehensive review, see Williams et al. 2012). In their review, Siegel and Beaulieu (2012) did not identify a single RCT targeting depression or anxiety and Williams et al. (2012) could not recommend the use of SSRI except on a case-by-case basis when targeting comorbid psychiatric problems.

There is established evidence for relatively few psychotropic agents in ASD. In fact, only risperdone and aripriprazole are FDA-approved for the treatment of irritability in ASD. Many drug studies are riddled with poor diagnostic evaluations, lack of blinded evaluations, and small sample sizes. For more comprehensive reviews on pharmacotherapy for ASD, we recommend Stigler and McDougle (2008), Tsai (2008), or Siegel and Beaulieu (2012).

Summary

There has been increased interest in behavior and emotional problems in children with ASD over the past 10 years. Whether or not these psychiatric syndromes are the exact same as those observed in typically developing children remains to be determined. Nonetheless, several recent well-conducted studies show very high rates of psychiatric syndromes in this population, especially ADHD and anxiety disorders. One issue where there is no debate is the fact that these behavior and emotional problems can lead to devastating consequences if left untreated.

On some levels, psychopathology research in ASD is in its infancy. Basic issues such as accurate diagnoses of psychiatric syndromes in this population remain elusive. A reliable clinical description of disorders, which includes an understanding of associated features and comorbidity, is a stepping stone for research on etiology, course, and treatment. The low incidence of the disorder and heterogeneous clinical phenotype make study recruitment quite challenging.

Despite the diagnostic challenges, it is encouraging to see that several large scale RCTs of behavioral and pharmacological treatments have emerged in the past decade. As these studies accumulate, we will learn about moderators and mediators of treatment efficacy. In spite of the progress, RCTs of behavioral, pharmacological, and combined treatments are desperately needed, especially in preschoolers.

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Training and Supporting Caregivers in Evidence-Based Practices

28

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Keywords
Parent training · Parent stress · Support groups

Given increase in prevalence rates of autism spectrum disorders (ASD) and evidence that intensive early intervention is important in prognosis, there is an increased need for services and interventions for children with ASD. However, several factors make the provision of these services difficult. First, there have not been enough providers to meet the increased need for services. Second, early interventions need to be intensive and ideally performed in the child's natural environment. Finally, intensive services involve many hours of therapy, which results in a high cost that may not be covered by health insurance. Given these factors, parent training in the techniques involved in intensive behavioral treatment may be a cost-effective and positive therapeutic alternative. As Schultz et al. (2011) point out, "… the comprehensive nature, ability to serve multiple functions, and adaptable form" of parent training is what makes it such an attractive option to providers and families of children with ASD.

Training parents to utilize behavioral strategies with children diagnosed with ASD is not a new practice. Lovaas et al. (1973) reported decades ago that parent training should be included in treatment for individuals with ASD in order to maintain gains made from an intensive behavioral program. Children whose parents were trained in behavioral treatment continued to improve 1–4 years post treatment (Lovaas et al. 1973). Although Lovaas et al. (1973) did not include information about the nature of training the mothers received nor was fidelity of treatment measured, this is an early example of the importance of parent training in the field of ASD.

Advantages of Parent Training Parent training methodologies present a number of benefits to both children and parents. Advantages to utilizing parent training include cost effectiveness, maintenance of treatment gains, and enhanced generalization (Matson et al. 2009). Parent training programs require less hours of intervention on the part of a professional, and group training programs can serve many families at once, maximizing the time of the professional while also lowering costs for families (for an example of the comparative costs see Anan et al. 2008). This then allows more families to access services.

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In terms of maintenance and generalization advantages, parent training provides a unique advantage in that the parents will be able to use the strategies in a variety of settings with the child. This then leads to increased consistency and a greater likelihood that children will be able to learn from the methods utilized. By nature, parents are with their children more frequently than anyone else. Children show improvements in functioning with the use of parent training (McConachie and Diggle 2007). Of the parent training studies reviewed by Shultz et al. (2011), 83 % of the studies reported improvements in target skills for children and a reduction of disruptive behavior was reported in 13 % of the studies.

Beyond the benefits experienced by the children, parents also receive direct benefits, including an increase in knowledge, skills, and performance (McConachie and Diggle 2007). By training parents to treat their children, parents also better understand effective treatment which can help them to be better consumers of treatment options in the future. Parents who have received training are able to become active participants in their children's development and treatment, which can be both empowering and rewarding. The therapy process may also be demystified through parent training, possibly helping parents commit more fully to the process (Matson et al. 2009). In a review of parent training studies, 87 % of the studies reported that parents increased in their ability to implement the skills they were taught, such as behavioral strategies (Schultz et al. 2011).

Secondary benefits of parent training include a reduction in stress and a decrease in depressive symptoms experienced by the parents (Schultz et al. 2011). The entire family may benefit from increased quality of life when problem behaviors decrease. In addition, research has indicated that parents are able to generalize the skills they learn to other children in the home, which may increase the consistency of their use of interventions when they can be applied to the parents' general day-to-day parenting practices (Laski et al. 1988).

State of Research in Parent Training Few systematic reviews of research regarding parent training have been written at this time and there is a lack of randomized controlled trials (RCTs) in the area of parent training. Until 2002, only two studies could be found that were RCTs (Diggle et al. 2002). Of the two studies reviewed by Diggle et al. (2002), one showed significant improvements when parent training was utilized, while the second demonstrated that therapist-mediated treatment produced significantly greater effects than parent interventions. The number of RCTs had increased to 12 when a review on parent-implemented interventions with children ages 1–6 years old was completed in 2007. However, many of the studies included in this review either lacked a control group, were single case designs, or used a pre- and posttest design (McConachie and Diggle 2007). Of the 12 studies included in the review, the majority utilized behavioral interventions. The authors reported that there was sufficient evidence to conclude that parent training can lead to improvements in social-communication skills. Research also indicates that parents have positive feelings toward parent training and find it helpful (Harris 1986). Several common elements can be found in successful parent training programs including "… being organized, targeting specific operationally defined behaviors which ld mcan be treated, establishing consequences, and maintaining consistency in programming" (Matson et al. 2009, p. 871).

With the importance placed on training parents in evidence-based interventions, it is important for clinicians and students to understand the empirical support underlying these approaches. The purpose of this chapter is to provide an overview of the research on parent training; how parent training techniques have been applied to different problem behaviors such as sleep, toilet training, daily living skills, and communication difficulties; and factors related to supporting parents and caregivers. Finally, a review of factors that influence parent training, including parental stress and cultural issues, will also be presented.

Variety of Modalities

There are many different types of parent training programs available for the treatment of children with ASD. Schultz et al. (2011) reviewed studies involving parent training, and of the 30 studies reviewed, 47 % focused on teaching communication using strategies such as Pivotal Response Training (PRT; Minjarez et al. 2011). In 80 % of the studies, the child was present during the training sessions. The majority of the studies (80 %) used a one-to-one training format, and 13 % used a group format combined with individual training sessions with parents and a trainer. In terms of the type of training, only 53 % used a standardized curriculum or manual. The majority of the studies reviewed used single subject research designs, and only 10 % included a control group for comparison. Many of the effective methods described in the literature rely on applied behavior analysis (ABA; Matson et al. 2009). As demonstrated by Schultz et al. (2011) parent training programs vary in terms of the location of services (home or clinic), length of training, group training, and instructional format.

Location of Services

Given that many families may live far away from a specialized treatment center and in-home services may be desirable in order to generalize learned skills, it can be difficult for families to receive the best services possible. This is especially true for families who live in rural areas or regions of the world that do not have providers who specialize in the treatment of ASD. To address these issues, several studies have investigated the effects of parent training conducted in different locations. For example, Baharav and Reiser (2010) developed a telemedicine model for the provision of parent training. In this study, families attended a once-a-week clinic session and then had a home-based session in which parents implemented the steps and the clinician supervised via remote access through the internet and a web camera (Baharav and Reiser 2010). This model was compared to the typical model of service provision in a speech and language clinic in which the families attended two weekly sessions. Baharav and Reiser (2010) found that the gains the children made in the clinic could be maintained with remote, telemedicine sessions in the home.

Other studies have demonstrated that center-based parent training can be an effective method. One study compared three groups of children who took part in either a center-based parent training with a concurrent manualized child play group, a 20-session home-based informal parent training program, or a wait-list control group (Roberts et al. 2011). Parents in the center-based program showed significant improvements in emotional well-being (as measured by three subscales on the Beach Family Quality of Life Questionnaire), while the parents in the other two groups did not. In fact, the parents in the home-based program demonstrated worsening in all domains of quality of life. Parents in the center-based program also demonstrated improvements in confidence and coping. The children in the center-based program improved on measures of social and communication skills at significantly greater rates than children in the home-based or wait-list group. The parents in the center-based program may have benefited from the small-group format and the structure provided by the program. Families in the center-based program also had an opportunity to learn the material in an environment away from their children for a significant part of the training, while the in-home training took place with the child present. It may have been more difficult for parents to focus on the material with their child there. The authors suggest that a center-based program may be the most cost-effective option, but they pointed out that it was not an option for all participants given they did not allow children with disruptive behaviors to participate in the center-based program.

Length of Treatment

Parent training programs can become very costly for families, and insurance companies are unlikely to cover the cost. These programs can also be very time intensive. For these reasons, short-term models have become a focus of the recent. Treatment programs vary in their length from workshops that take place over several days to programs in which continued consultation is provided by psychologists after group instruction is completed. Research into these different programs has demonstrated that they are efficacious.

In an effort to provide services to families living far away from parent training centers, training could be brief in duration in order to decrease the amount of travel and expense incurred by the family. Koegel et al. (2002) created a model in which families traveled to a specialized autism center in California and spent 5 days receiving 25 h of training in PRT. The training was individualized, intensive, and allowed for generalization by choosing many different common environments in which the parents could implement the strategies with the coaching of the clinician. A concurrent, multiple baseline across participants design was used and five families participated. The families were given a copy of *How to Teach Pivotal Behaviors to Children with Autism: A Training Manual* (Koegel et al. 1989) to read about the different motivational techniques they would be learning. Once the parents returned home, they sent videos to the trainers in order to determine fidelity and the child's progress. The parents reached an 80% reliability level in the performance of the interventions by completion of the training. They demonstrated generalization and maintenance to their home environment upon follow-up between 3 months and 1 year. Parents were observed to create more opportunities for their children to interact and more appropriate use of natural and positive reinforcement. The results suggest that it could be feasible and effective to implement a brief, intensive parent-based treatment program for young children with ASD. Several possible limitations to this model are present including the fact that families had to travel and take an entire week away from home and work to receive the training. This may not be feasible for families with multiple children or for low income families who cannot afford to travel or take extended time off of work.

Coolican et al. (2010) examined an even briefer model of PRT that only required 6 h of training with the parents. They found that child communication and parent skills increased and were maintained 2–4 months later. When the parents improved in their ability to implement the techniques, improvements were also seen in child communication. Brief training models such as the ones presented demonstrate the value of intensive, time-limited parent training, and that the gains made during these short interventions can be maintained over time.

Group Training

Another training approach utilized to address time and money restraints is group methods that teach multiple families at once. One study examined an accelerated format of PRT for families of children who had recently received a diagnosis (within past 6 months). The model was based on a manualized PRT training, but it was condensed into 12 weeks. The researchers found that an accelerated group model could be helpful and lead to increased communication in children. This study, along with many others that involved group instruction, demonstrated that families appreciate a group format because it normalizes the families' experiences, and an added support is included from other families who are experiencing the same difficulties (Anan et al. 2008; Harris 1986; Minjarez et al. 2011; Pillay et al. 2011; Stahmer and Gist 2001).

Instructional Format

In an attempt to determine the appropriate instructional format for different skills taught to parents, Lerman et al. (2000) conducted a study in which the most cost-effective approach was used initially and adapted with more direct instruction as needed when the parent had difficulty with a skill. Initially, skills were taught using written directions and progressed to more hands-on training with modeling and coaching. All three mothers met the criterion for several skills with only verbal and written directions, but they all required more intensive instruction for at least one skill. Parents did well with planned ignoring of attention-seeking behaviors, but they all needed more instruction with praising their child as a form of positive reinforcement. The authors suggested that clinicians create a criterion for each skill and attempt the most cost-effective form of training first, such as written, verbal, or group instruction. However, clinicians following this model should be prepared to provide feedback and coaching for skills that parents are not able to perform at criterion using the less expensive methods.

Comprehensive Treatment Programs

Several comprehensive parent training packages have been created and typically combine a number of the training modalities already discussed (e.g., individual and group instruction), intervention directly to the child, as well as home- and center-based services. These packages have the most research available and can be very appealing for families of young children who need a variety of services. These comprehensive programs typically address a wide range of behavioral and communication difficulties while teaching general behavior management strategies to families.

TRE-ADD Preschool Parent Training Model

The Treatment, Research, and Education for Autism and Developmental Disorders (TRE-ADD) Preschool Parent Training Model was created for families in Canada who were not yet receiving provincial intensive behavioral interventions funds. It was also viewed as a first step in the process of treating a child with ASD (Perry and Condillac 2010). TRE-ADD is a comprehensive, 3-month intervention that first provides diagnostic evaluations and then a combination of group instruction, one-to-one instruction with staff, and coaching of the parents in using what they learned. The families participated once a week for 3 h for an 11-week period. An interesting component of this program was that the children were present throughout all of the sessions either receiving individualized behavioral training from a therapist, therapy in the form of newly learned skills from their parents, or participating in craft or play activities to increase social skills.

Perry and Condillac (2010) evaluated the TRE-ADD program by comparing the following groups: (1) children enrolled in the TRE-ADD program; (2) a small wait-list control group receiving few services in the community; and (3) another control group of children from the wait list receiving services from other providers. Results indicated that the children in the TRE-ADD program significantly improved in all areas on the Brigance subscales except Pre-Speech, while the group without services did not improve, and the group with services only improved in Expressive Language. TRE-ADD parents improved in their knowledge of behavioral principles, did not report increased family stress, and were satisfied with the program. However, parents in the TRE-ADD did not feel very confident in implementing their skills and felt that they needed further consultation. Upon follow-up, it was found that the majority of the children were not receiving intensive behavioral services, either performed by their parents or through outside sources. The authors pointed out that parental satisfaction may not be an optimal outcome measure because although parents were happy with the program, they were not implementing it after it ended. Their reported lack of confidence in implementing the skills may be a partial explanation for the lack of follow-through after the program ended. If parents did not feel comfortable with the skills, they most likely did not use them on a regular basis.

Stepping Stones Triple P

Triple P, a parent training model based on positive parenting strategies principles, has been adapted into a training program for parents of children with disabilities and renamed Stepping Stones Triple P (Whittingham et al. 2009b). Stepping Stones includes the strategies from Triple P, such as praise and planned ignoring, as well as strategies specifically chosen for children with disabilities, such as skill acquisition, and it was further adapted to be used with parents of children with ASD. The program takes place in a partial group format with four to five families per group. Group instruction was used for teaching parenting strategies and individual sessions were used to provide practice and feedback. It should be noted that this program is not designed to be a sole source of intervention for children, but instead used to specifically address dysfunctional parenting strategies and behavior problems.

A randomized control trial was conducted with families of children diagnosed with autistic disorder or Asperger's disorder, although all children in the study were verbal and most likely high functioning (Whittingham et al. 2009b). The researchers found a significant reduction in child problem behaviors for the treatment group and that change was sustained 6 months following treatment. There was also a significant reduction in dysfunctional parenting strategies; specifically, the parents were less permissive, overreactive, and verbose. Satisfaction in parenting increased among the treatment group, and parental self-efficacy was increased after 6 months of follow-up. Stepping Stones Triple P appears to be an appropriate option for parent training for families with a high-functioning, verbal child with ASD who is demonstrating behavior problems, although its utility with children of other levels of functioning has yet to be demonstrated.

Group Intensive Family Training (GIFT)

The Group Intensive Family Training (GIFT) program provided 12 weeks of parent training for preschoolers with ASD (Anan et al. 2008). Parents were taught behavioral principles, particularly those related to PRT and hands-on instruction in a group format with six other families. Enrollment was staggered in such a way that new families were always exposed to families who had been in the program for several weeks in order to promote support and provide a model of parents who had increased their skills.

Parents worked individually with staff during the first month of the training and an individualized treatment plan was created for each child by a psychologist. Parents also attended a 12-h didactic about behavioral principles in order to help parents determine if they would like to commit to the training. An interesting component of this training was that in month 3, the parents brought in a spouse or other family member to teach the other caregivers the skills learned in the group. This served to solidify the parent's skills, as well as to involve another person in the treatment of the child. The children showed significant gains in short-term cognitive and adaptive functioning. It could not be determined if this was solely due to the parent training, given that there was not a control group and many families were also utilizing other services concurrently.

Chinese Parent Training Program

As the support for parent training interventions grows, it is encouraging to see the increase in parent training research in other parts of the world. For example, a parent training program in China provided 20 h of training to parents over the course of 4 weeks (Wang 2008). The parents participated in group training that included education about ASD, applied behavioral analysis, functional behavior assessment, scheduling, appropriate prompting, and how to follow their child's interests. They also received individual in home training once a week for up to 2 h from the trainer that involved live modeling, coaching, and applying interventions. This is an interesting study because they examined how the training impacted the parents' responses to their children in a videotaped interaction. It was found that parents in the training group were more responsive to their children and demonstrated more positive affect toward their children following the training. The researchers did not measure child behavior in any way, so it is impossible to determine whether the change in responsiveness and affect made an impact on the child, but it is notable that training helped parents to feel more positive toward their child, and there was a decrease in their overbearing interactions. It is possible that parents felt more comfortable with their child once they gained skills for interacting. While this study utilized many of the same behavioral interventions as other studies reported, it is encouraging to see the utility of these methods in culturally diverse populations.

Manualized Treatment Programs

In addition to available comprehensive treatment programs, there are manualized treatments that focus purely on parent training without additional in-home or child-focused services. These programs tend to focus on interactional patterns between the parents and children and encourage the parents to create situations in which their children can learn new skills. The two most relevant manualized interventions currently available are PRT and Relationship Development Intervention (RDI).

Relationship Development Intervention (RDI)

RDI is a very different type of parent training that has received attention recently in that it focuses on cognitive-development, experience-sharing difficulties, and flexibility in relationship situations instead of behavior (Gutstein et al. 2007). RDI addresses "…the distinct patterns of perceptual, cognitive, and emotional difficulties unique to individuals on the autism spectrum through a parent driven intervention model" (Gutstein et al. 2007, p. 398). Parents participate in 6 days of workshops about the theory and principles of RDI, a planning session, and weekly or biweekly consultation sessions. Parents learn how to provide opportunities for children to engage in more flexible ways to solve challenging situations and behaviors. They are then trained on how to include these opportunities in their daily lives.

In a study of the effectiveness of RDI, children between the ages of 20–96 months with standardized scores of at least 70 on measures of cognitive functioning were followed for 30 months after their parents received training. The children in the study were more socially related, as measured by the Autism Diagnostic Observation Schedule (ADOS) and engaged in more reciprocal communication following treatment. The gains that the children made in functioning were maintained over the course of 3 years. The authors also reported that parents claimed to experience a significant improvement in their quality of life after starting RDI (Gutstein 2009). They also reported that children were able to handle situations requiring flexibility as well as typically developing children more than 70 % of the time, according to their parents.

Several limitations exist with this study on RDI. Scores on the ADOS was used as a primary outcome measure, but initial ADOS scores were not available for several participants. In addition, the study did not include a control group. Another potential limitation is that the families sought out RDI, meaning they already believed in the treatment before participating which may have biased their reports of effectiveness.

Pivotal Response Training (PRT)

As has been previous discussed throughout this chapter, PRT is a parent training treatment approach that has been well studied. Pivotal response training has also been taught to parents via a group format in a much shorter-time period. A 10-week parent education group format taught PRT during 90-min weekly sessions plus one 50-min session (Minjarez et al. 2011). The instruction was based on Koegel et al.'s (1989) manual about PRT. The model used in this study was unique because it required the parents to tape 10-min segments each week and they showed them to the group to receive feedback on their implementation of the skills and suggestions for future use of the skills. There were six sessions in which parents presented videos. This allowed for weekly feedback, similar to what would be given live in individual sessions, but in a much more cost-effective environment. The results supported a group training model for addressing language deficits and demonstrated that parents could learn PRT in a group format. The children in the study increased in their communicative language over the course of the training program. Specifically, children increased their use of functional communication.

This model may be an excellent complement to other services children may receive and may increase intervention intensity given children will have trained interventionists, their parents, with them the majority of the time. The positive results of this study support that a short-term group model can be effective. Granted, there was not a control group and the study needs to be replicated, but the continued feedback given via video is an interesting concept and could be very helpful for parents. The lack of child involvement in the training sessions may have allowed parents to more fully focus on what they were learning, without worrying about their child's behavior or needs. It also allowed them to receive support from other parents and see others experiencing similar struggles and successes each week with their children.

Targeted Parent Training

The previously mentioned parent training programs focused on teaching parents behavioral or relational strategies to treat the core symptoms of ASD and general behavioral management skills in the hope that parents can utilize what they learned for a variety of difficulties their children may experience. Other parent training and education programs have targeted specific symptoms or difficulties that children with ASD might experience, such as sleep, toilet training, daily living skills, and social communication skills. Many of these programs use ABA techniques along with other strategies tailored to address the specific behavior problem. The sections below describe many of the available parent training programs for specific symptoms.

Sleep Difficulties

Difficulties with sleep are a common problem among individuals with ASD. Individuals with ASD may have insomnia, night awakenings, or early morning waking (Reed et al. 2009). When there is a child who has sleep difficulties in the home, parents also get less sleep, which can be frustrating and exhausting. Core behavioral and communication difficulties found in ASD may impede children from establishing effective sleep behaviors. Difficulties with emotional regulation and transitioning from activities are examples of characteristics that can impair sleep routines.

Reed et al. (2009) created a 3-day workshop to teach parents of children with ASD how to use behavioral strategies to promote better sleep hygiene in their children. The pilot study utilized workshops, and no control group was used. Parents were provided with education about sleeping difficulties and taught how to develop an effective bedtime routine with visual supports, as well as reinforcement strategies for nighttime awakenings and appropriate sleep hygiene. The authors found that after training, there was a decrease in insomnia as well as hyperactivity, self-stimulatory behavior, and restricted behavior. There was no change in the number of nighttime awakenings. The children in the study had a wide range of language abilities, indicating that this could be effective with children of different levels of functioning. Children who were prescribed medications also appeared to do well with the interventions. Parents reported high satisfaction with the training and indicated that they felt they had more skills to handle sleep difficulties. One interesting finding was that parental stress was not significantly decreased after sleep difficulties were addressed. It is possible that parents were experiencing stress for many reasons besides sleep or there was not enough time for the new sleep patterns of their children to be in place for them to feel the effects of the changes. It was recommended that the study be replicated with a control group and that a trial be conducted with adolescents who could receive some of the education directly along with their parents.

Toilet Training

Incontinence is a common problem among individuals with an ASD, and it is very frequently addressed in clinic visits to psychologists and other providers. Primary caregivers are likely to be the best implementers of toilet-training protocols because they are with the child the most frequently, they can read subtle cues in their children that others may not be aware of, and they have the most motivation for the training to be successful given that incontinence can be a very stressful problem. Kroeger and Sorensen (2010) adapted a toileting protocol that was created by Azrin and Foxx (1971) to toilet train individuals in a residential facility. The adapted protocol was used to treat two boys diagnosed with autism. One of the children was 4 years old and he had never had any toilet training, while the second was 6 years old and had been resistant to past toilet-training attempts. The program included increased fluids, scheduled sitting on the toilet, positive and negative reinforcement for voiding in the toilet, redirection for accidents, and scheduled sitting in a chair to help increase self-initiations to use the toilet. The program did not include any type of punishment for inappropriate urination. Parents were trained in the program on the first day before it was implemented, and they were able to observe the trainer implementing the procedure with the child for the first 3 h. The next 3 h consisted of the parents implementing the program with the trainer providing coaching. After that the trainer left, but was available by phone for consultation, and the written protocol was provided for the parents to reference. Once the boys achieved continence with the first toilet in their home, they were then trained to use another toilet at home and later to use toilets at places they frequently visited, such as at school or at their grandparents. This program was successful within 4 days and was completely discontinued by 2 weeks. At the time of publication, the participants had maintained continence for over 4 years. The authors suggest that maintaining continence can improve the quality of life of the children, as they can participate in more activities and go more places, and for the parents in that stress is lowered.

Daily Living Skills

Daily living skills can be another area of difficulty for children with ASD, and it becomes difficult to achieve independent living if an individual is unable to conduct daily hygiene skills, such as brushing one's teeth or taking a shower. One study taught parents how to use ABA to teach their children to complete these activities (Cavkaytar and Pollard 2009). This study specifically compared the difference between the mother solely teaching the skills and a collaboration between a paraprofessional and the parent in teaching the same skill in different settings. The authors found the child who received training in two environments (by both the mother and the paraprofessional) achieved the skills the quickest and the mother who did not have the assistance of a paraprofessional throughout the process felt more stressful and was only on the verge of achieving two out of three skills. The authors emphasized the importance of encouraging collaboration between parents and other professionals when utilizing parent training.

Social-Communication Skills

Communication and social skill deficits are core areas of impairment for children with ASD. Deficits can present as lack of appropriate play skills, lack of verbal communication, difficulties with conversation skills, and a lack of peer relationships. These areas are typically focuses of intervention in order to increase communication and social skills. The following section describes several parent training interventions used to address these areas.

Script fading, a technique used to increase spontaneous speech during play activities, was taught to the parents of three children to generalize verbal imitation at home (Reagon and Higbee 2009). The parents in the study were quickly able to learn the technique and implement it at home with 2 h of training. The parents then used a voice recorder to play the scripts that they created for the children. All three children were able to acquire the scripts as well as increase their unscripted initiations. The children also began to initiate play with their parents with toys for which a script had not been provided. The technique appeared to generalize across types of toys. Follow-up data were only provided across 2 weeks of the study, so it is difficult to determine if the effects lasted in the long term. This could be an appealing parent training technique because it may lead to increased positive interactions between parent and child as well target language during play activities.

In another study, parents were taught improvisation training as part of a Picture Exchange Communication System (PECS; Ben Chaabane et al. 2009). The purpose of the technique was to teach children to request items based on characteristics of the toy, such as color and shape. Parents were trained by the researchers in how to implement the technique, and they began using it at home with their child when they were at 90% accuracy. Only two children were involved in the study. There was an immediate and substantial increase in correct improvisations after the mothers implemented the technique. Mothers reported that it was easy to implement and that they would continue to use the technique in the future. Unfortunately, there was not maintenance data collection so it is difficult to know if the gains continued in the future.

Another important social-communication skill that is difficult for children with ASD is joint attention. Joint attention is "the ability to coordinate attention between an object and a person in a social context" (Rocha et al. 2007, p. 154). Joint attention is characterized by both initiations and responses, with responses usually developing first. This is a very important aspect of effective social communication, as it allows an individual the opportunity to pay attention to the same objects as others and opens the door to social interactions.

A parent-implemented program involving discrete trial training and PRT was created to increase joint attention responding (Rocha et al. 2007). Parents were individually instructed in the techniques to increase joint attention bids, and they were coached by the trainer in implementing the skill in the treatment office. Parents were then videotaped at home to see if they were implementing the techniques in another environment. Following training, parents increased the amount of joint attention bids they provided, and children increased in both joint attention responses and initiations. Parents demonstrated fidelity to the intervention, but upon follow-up, two of the three parents stopped utilizing the techniques. However, two of the three children continued to respond to joint attention bids. All of the children demonstrated improved joint attention responses when they were assessed by the evaluator, indicating that this method may promote generalization across adults. Given that parents stopped utilizing the skills they learned, it may be important to provide follow-up or booster sessions to encourage them to keep focusing on developing this skill in their children (Rocha et al. 2007).

Another valuable approach to social skills training is to involve children with ASD in social skills groups while also providing training to parents about how to foster social skills in their children. Frankel et al. (2010) adapted Children's Friendship Training, an established social skills training model at the University of California Los Angeles (UCLA), to be used to treat high-functioning children with ASD. Children were integrated into groups of children who had behavior difficulties but not ASD. Parents were given formal training for 1 h a week while the children received group therapy. Parents were taught about the skills the children were learning each week and were highly involved in the completion of their child's homework each week. Parents were taught how to help their children plan play dates and coordinate these events with other parents. They were also instructed on how to assist their children with peer interactions and what rules to enforce with their children during the interactions.

This is a particularly interesting approach given that many parents of children with an ASD at times also have social difficulties. The hope of the researchers was that parents would implement what they had learned about promoting and supervising play dates in the long term after the completion of the study. The results demonstrated modest treatment effects after participation in the group. Parent report showed an increase in hosted play dates and a decrease in the amount of time spent on electronics during the play date. Parents also reported that children had more self-control and a moderate improvement in assertiveness, reduction in conflict on play dates, decrease in internalizing symptoms, and decrease in externalizing symptoms. Children demonstrated improvements in popularity and decreased loneliness, although this was not maintained at the 3-month follow-up. On outcome measures, there was a significant change in social skills in comparison with the delayed treatment group. There were also significant changes found on parent outcomes, which may have been related to the fact that parents were active participants in the treatment and were primed to see improvements. In order to determine if this is an effective model, independent ratings need to be utilized in regards to play-date behavior. In addition, it may be helpful for future research to include a treatment group in which parents did not receive weekly training as a comparison to the model used in the study.

Very similar to Child Friendship Training, Program for the Enrichment and Education of Relational Skills (PEERS) group therapy program employed a parent training element in addition to a social skills group for adolescents (Laugeson et al. 2009). Parents attended separate concurrent sessions where they were instructed on how to supervise their teens implementing skills they learned in the social skills group. The training was adapted from the Children's Friendship Training to be more applicable to teenagers. The participants in the adolescent group were all diagnosed with an ASD, which differed from the Children's Friendship Training study. Parenting sessions focused on helping teens expand their social network, find appropriate friends, and provided strategies for parents to use when supervising get-togethers to avoid being intrusive. The adolescents in this study demonstrated improvements in knowledge of social rules, an increase in the number of get-togethers they hosted, and better quality of relationships as compared to a delayed treatment control group. Parents reported a significant improvement in overall level of social skills in their children. However, it is possible that parent reports may have been biased given the fact that they were involved in the training.

This model of involving parents in social skills training and teaching them ways to foster the skills taught at home seems like an excellent next step in social skills training. One question, though, is whether whole sessions are needed in order to teach parents this information or if a briefer format (such as handouts and homework activities) could achieve the same results. Many social skills groups attempt to involve parents through the use of weekly homework, and one has to wonder whether one or two sessions in addition to the homework would be just as effective.

Feeding

Individuals with an ASD may present with a variety of feeding problems that must become the target of intervention. Many times, they are resistant to trying new foods, and parents report sensory issues with different types of foods. Food selectivity, the rejection of certain foods, is a very important focus of treatment due to the importance of adequate nutritional intake. Najdowski et al. (2010) argue that ABA treatment for food selectivity should occur in the home by the parents for many reasons, including that treatment will need to be carried out in the natural setting by parents every day and generalizability across people and situations is not guaranteed. Parents were taught how to implement differential reinforcement of alternative behavior, non-removal of a spoon, and demand fading. The results demonstrated that parents can be trained to implement the techniques. In addition, their children increased their consumption of non-preferred foods and decreased inappropriate behaviors at meal time. Parents collected accurate data and demonstrated treatment fidelity. The authors believe that training parents to implement a program such as this for food selectivity can reduce costs and time while increasing generalizability and maintenance. This could be an excellent way for families to save money while also providing quality treatment for their children.

Parental Support Services

Parents of children with ASD experience high levels of stress and psychological distress. They tend to experience higher levels of stress than parents of typically developing children (Singer et al. 2007). This may be explained by the high level of assistance their children may need, a responsibility to coordinate services, and difficulty interacting with their children. Parents may themselves benefit from parent support services separate from parent training, and this has been a developing area of research. Parental self-efficacy is also an important area of research, given it is important for parents to feel confident in their skills before they act as providers to their children.

Parental Stress

A meta-analysis of the impact of parenting interventions on reducing stress and depressive symptoms in parents of children with developmental disabilities found positive results for behavioral parent training, cognitive behavioral therapy for parents, and methods that combined several types of treatment (Singer et al. 2007). Reduction of parental stress and depression was found to be a secondary benefit of behavioral parent training. The authors pointed out that the reduction of problematic behavior in children could be both a cause and an effect of the change in parental stress and affect. Studies that employed cognitive behavioral strategies to help reduce stress and depressive symptoms in parents were also found to be effective. Finally, studies that employed a multicomponent model of interventions that addressed both problem behaviors in children and parental well-being were shown to be the most effective of the three types of interventions. The authors found that there is evidence-based support for interventions to lower parental stress for middle class Caucasian families. It was emphasized that more research is needed with culturally diverse and lower socioeconomic families.

Support Group with Training

Parents of children with ASD experience high levels of stress, and many parents who have recently received a diagnosis for their children are seeking information and support along with training. Stahmer and Gist (2001) examined how the inclusion of a 12-week support group for parents might impact an accelerated PRT program. Parents received either PRT individually with a therapist or PRT and a weekly support group with other families and a facilitator. The support group focused on providing information about the diagnosis and family life with a child with ASD, while also fostering relationships among group members. The researchers found that the parents in the support group plus PRT condition performed significantly better at mastering the PRT techniques. Increased improvement of children's skills was then associated with mastery of the skills by the parents. It is not clear, however, how the support group impacted the mastery of skills in parents. Possible explanations for this effect are that the parents may have discussed the skills they were learning which led to better understanding, and the group provided a forum for discussing stress which allowed the parents to focus more fully on the PRT techniques during training with the therapist. Additional explanations include that the additional support may have helped the parents to realize how important the training process was or the families learned from each other about other programs that they utilized. A potential limitation to this study was that a requirement of participation in the program was to refrain from starting any new treatment during the training. Also, random assignment to groups was not conducted, so it is impossible to determine if any characteristics of the participants impacted the results. This is an interesting concept that deserves further exploration as a support group model may be a helpful and inexpensive addition to parent training.

Parental Mental Health

In a study examining the impact of parent education on the mental health and adjustment of parents of preschool children with ASD, researchers randomly assigned parents to a parent education plus behavior management intervention or a parent education plus counseling intervention group (Tonge et al. 2006). Parents in both groups had improved mental health at the end of treatment, but interestingly the parent education plus behavior management group had the greatest effect in alleviating symptoms of insomnia, somatic complaints, family dysfunction, and anxiety at the 6-month follow-up. One explanation for these results is that the parents' mental health difficulties were a result of the continued difficulties with their children and behavioral training provided skills for them to more effectively interact with their children. This further supports the need for parent education and training to be an addition to any ASD treatment program given the benefit it can serve in terms of offering benefits to the parents and the children. Laski et al. (1988) found that parent training was indicated in decreasing maternal depressive symptoms.

Family Well-Being

Another positive impact of parent training programs could be to improve the well-being of the entire family. Zingale et al. (2008) implemented three types of parent training programs with individuals with intellectual disabilities. They found that parents reported improved well-being and quality of life for the entire family following treatment. Parents reported that the treatment was useful and they experienced increased confidence, a clearer understanding of their child's diagnosis and prognosis, and an ability to normalize the overwhelming feelings they experienced as therapists or educators for their children. Laski et al. (1988) found that parents were able to generalize their skills to other children in the home.

Acceptance and Commitment Therapy

Blackledge and Hayes (2006) studied the possible usefulness of Acceptance and Commitment Therapy (ACT) with parents of children with ASD. They hypothesized that ACT may be helpful for parents given that they experience distress, but their difficult thoughts and feelings are not exaggerated or inaccurate in light of the challenges that their children face. ACT emphasizes the acceptance of uncomfortable emotions and clarification of the parent's own goals and values. A 2-day workshop was provided to participants that included instruction and experiential exercises. The authors reported that general distress and depression levels decreased at the end of treatment, and this was maintained after 3 months. Unfortunately, there was no control group, so it is difficult to determine if the changes were due to the treatment or other factors. The authors suggested that if future research supports the use of this intervention, it may be helpful to include ACT as an addition to evidence-based parent training programs to help parents manage their own stress.

Mindfulness

Another therapy strategy that has been applied to parent training is mindfulness training. Recently, evidence has been found that the use of mindfulness during parenting can be effective at changing children's problem behavior by changing the interactions between parents and children (Singh et al. 2006). Being mindful is described as "having a clear, calm mind that is focused on the present moment in a nonjudgmental way" (Singh et al. 2006, p. 170). Three parents were taught mindfulness techniques through individualized training sessions, and they then put it in practice at home. All three mothers had received previous parent training in various formats including teaching language skills and behavior management. They were encouraged to use their typical parenting strategies throughout the study in addition to the mindfulness training.

Problem behaviors that were measured included aggression, noncompliance, and self-injury throughout the day by both the mother and the father to achieve reliability. A significant change was found in problem behavior in all three areas. Given that mindfulness encourages the parent to be "in the moment" and to focus on the current behavior, without thinking about past parenting experiences or beliefs, it is possible that parents were better able to employ strategies they had learned previously more effectively with the change in mindset. The focus in the mindfulness training was not to try to change or replace problematic behaviors, but instead to change the milieu of the family through unconditional acceptance that encourages positive changes. Singh et al. (2006) suggest that by employing unconditional acceptance of their children, mothers ceased trying to impose their own will on the child. This approach could be a very attractive option for families who struggle with a problem-focused approach to parenting. It could also be a helpful strategy for families who have recently received a diagnosis for their child and are having difficulties accepting their child.

Strength-Based Parent Training

At times interventions with parents can become very negative in nature as the focus becomes solely on the problematic behaviors of the child. There is the risk that parents can become very discouraged in both their child and their own parenting abilities. Positive psychology as a therapeutic framework has become more popular in the field of psychology as a whole and this approach has also been applied to parent training methods. Steiner (2011) studied the effects of strength-based statements versus deficit-based statements made by the provider during PRT-parent education sessions and the effect on parent affect toward the provider and child as well as the parents' own statements regarding the child's behavior. An example of the type of positive statements made by providers was "Your child has many interests and that is a good thing. One way to help him focus on one toy…." As opposed to, "Your child has difficulty with attention and is very distracted right now. One way to help him focus on one toy…."

The results of this study demonstrated that parents made more positive statements about their child during the strength conditions and their affect was more positive toward the provider and the child. The parents were more playful with their children when they were in the strength-based phase of the treatment which the authors hypothesized might lead to higher rates of child responsivity. However, the study was limited in that there was no control group and the interventions were varied throughout each session, making it difficult to evaluate any long-term effects. Steiner (2011) reported that these results suggest that the presentation of parent education programs may benefit from being more positive in nature. It was also hypothesized that this approach may be helpful with parents of older children, as they may have already tried many approaches and become discouraged about the lifelong challenges of their child's behavior. Research has shown high attrition rates in parent training programs for parents of older children (Dishion and Patterson 1992), so the applicability of interventions such as this strength-based approach for older children is worth further study.

Parental Self-Efficacy

One important question to consider is whether parents feel that they are capable of implementing the training they receive. Their self-efficacy concerning their interactions and treatment of their children is one way that this has been researched. Raj and Salagame (2010) examined domain and task-specific self-efficacy in mothers after they were trained on how to elicit requests from their children. A sensitized coaching model was used. Sensitized coaching involved the use of data collection to allow the mothers to see the progress that they had made with implementing the skills. Parents in a sensitized parent coaching group demonstrated greater task-specific self-efficacy following the training as compared to a typical parent coaching group.

The focus on parental self-efficacy highlights an important concept for practitioners to keep in mind. Specifically, it may be helpful for providers to be able to either tell or demonstrate to parents the progress that they and their children have made throughout the intervention. Just as positive reinforcement is helpful for children, parents should also be positively reinforced for the growth and changes that they make. Parents who are more confident in their parenting skills and their ability to help their child are more likely to participate in and consistently implement interventions. In another study, as parents became more confident in their learned skills, they provide more opportunities to interact for their children (Baharav and Reiser 2010). Of interest was the fact that parents' sense of self-efficacy was correlated with whether they thought the intervention was effective. This is yet another indication of the importance of ensuring that parents feel comfortable and confident in their skills before they are asked to implement them.

Research has demonstrated that in many ways, parent training can be effective at changing children's behavior, but questions remain such as whether parents feel satisfied with the training they receive and whether they feel confident to implement it. Dillenburger et al. (2004) examined parental perception of ABA training programs when they have been trained to implement them with their own children. The parents in the study were educated in the general principles of ABA in order to help them address various behavior difficulties with their children. The parents received class-like training over an 18-week period, and an ABA professional visited them in their homes on a weekly basis to supervise their implementation of what they learned in the class. Families involved in the study included those who had been receiving ABA services for many years and others who had only been receiving services for approximately 6 months. In an evaluation of the training, parents reported that ABA had a significant impact on their child's development. They also reported that the outcomes of the training had made differences for the entire family and raised the confidence and empowerment of the parents. Parents felt that the interventions they learned were appropriate for their children and they were satisfied with the goals of the interventions. The authors hypothesized that the general nature of the training had an impact on the child on a daily basis in many different situations. Even the families who were relatively new to ABA treatment felt that it was helpful. It is particularly noteworthy that the parents felt that the training was important to the quality of life for the entire family, not just the affected child.

Sofronoff and Farbotko (2002) examined the differences among group parent training, individual parent training, and a control group for children with Asperger's disorder. The authors also measured parents' self-efficacy, or how confident parents felt in their ability to handle their child's behavior problems. Results indicated that there was a significant decrease in problem behaviors in the children as reported by the parents, and there was an increase in parental self-efficacy across both intervention types. There was no change in child behavior problems and a decrease in parental self-efficacy in the control group. In terms of differences between the two intervention types, parents who participated in the workshop showed a slight drop in efficacy at a 3-month follow-up which the authors hypothesized could be due to the complexity of the strategies or difficulties in implementing the strategies. They suggested that booster sessions may be helpful to maintain parent motivation and gains that were achieved. The authors also examined gender differences in self-efficacy between the mothers and fathers. Mothers showed an increase in self-efficacy that was maintained at a 3-month follow-up, while fathers showed no changes in self-efficacy. It was hypothesized that this could be due to fathers not having as many chances to practice the skills or that the fathers themselves had symptoms of Asperger's disorder, and they may have had difficulty with the oral format of the presentations. This study also demonstrated that a 1-day workshop can be helpful to families.

These results highlight the need for clinicians to address parental stress in methods beyond targeting the behavioral problems that may be contributing to this stress. While those who specialize in treating children with ASD may not necessarily have the expertise to provide therapeutic interventions to parents (e.g., cognitive behavioral therapy), presenting options and referrals to parents to obtain such services is highly recommended. This may mean having direct conversations with parents about their level of distress and coping skills and encouraging parents to seek therapy for themselves. Referrals to psychologists and therapists in the community should be kept readily available by clinicians in order to assist parents in need of direct intervention.

Parent Characteristics

Little is known about how family or parent characteristics can impact success in a parent training program. This is unfortunate given that training programs could be adapted to promote success among families if specific barriers were identified. Knapp and Deluty (1989) found that middle class parents were more likely to be able to learn from verbal or written instructions while low socioeconomic parents needed more feedback and live instruction. Many of the studies reviewed in this chapter did not report demographic information about families and of those that did, many of the parents had at least some college education. It would seem that the parent training methods being used currently should be studied in lower socioeconomic families or with parents with less educational attainment in order to determine if these results can be generalized to other populations. Also, more research needs to be conducted pertaining to the characteristics of parents that perform well in parent training programs. There may be families for whom parent training is not appropriate, and it would be helpful for clinicians to be aware of these characteristics in order to provide the most effective services for each client.

Given that this is an area that is lacking in the ASD literature, research about parent training with children who have other disorders may be helpful to examine. A study about children with disruptive behavior disorders found that parents of older and younger children were both likely to benefit from parent training, but parents of older children were more likely to drop out of the parent training study (Dishion and Patterson 1992). The study also found that the families who dropped out had reported less total aversive behaviors than the families who remained in the parent training program. Although this was not a study about families of children with ASD, these results should be considered in creating parent training programs, and it should be explored in future research studies. Families of older children who have fewer behavior problems may not be willing to commit to parent training programs, or they may need less intensive services.

Impact of Parental Stress

Robbins et al. (1991) examined the characteristics of parents and children in an early intervention parent training program. The program consisted of approximately 5 h per week of individualized intervention that utilized applied behavior analysis and positive approaches to behavior change. Parents in the study were experiencing a high level of stress and their child was a significant source of the stress. In terms of overall stress in their lives, there was a significant, inverse relationship between parental stress and the amount of progress their child made in the program. This relationship was correlational, so a direct cause and effect relationship cannot be determined. Also, of interest is the fact that all of the children who made high levels of progress were from two-parent households. The authors suggest that parent training should be individualized in order to address any difficulties the family might have and to also consider that for some families, intensive parent training may not be the most appropriate option. If there are many life stressors, parents may not be able to give adequate attention and time to an intensive program with their children. For some families, other services may be more helpful such as respite care, support groups, and in-home assistance. Although, Smith et al. (2000) found that parental stress was reduced through the parent training. This suggests that parent training may actually help lower stress for parents, which will help interventions be more effective.

The topic of parental stress is interesting and worth examining further. The impact of parental stress on child outcome was also demonstrated in a study of an in-home treatment program (Osborne et al. 2008). Although they found that children showed greater improvements when interventions were time intensive, the interventions were not as effective when parenting stress levels were high.

When parents had high stress levels, fewer gains were produced by the children in both the higher and lower time-input groups and the most pronounced impact was with children in the high time-input group. The effect was specifically significant on education and adaptive behavioral functioning, but not in regards to intellectual functioning. The authors suggest that it may be helpful to measure parenting stress levels before beginning a parenting education plan in order to make recommendations for the parents to seek out stress-reduction services before the program begins in order to help insure the most progress possible for the child.

Clinicians conducting parent training should be gauging the stress level in the parents and must be prepared to provide resources to help the parents lower their stress and gain assistance with their children. It is not surprising that parents of children with ASD experience a high level of stress or that stress can have a negative impact on treatment. The impact of the parental stress could be due to several factors, including the influence of stress on the parent's behaviors or their ability to even fully commit to learning and utilizing the program. It may also be helpful for parent-training programs to include education or counseling about parent stress. Also, of interest is that parents' affect was observed to improve during training and post training, possibly indicating a reduction of stress (Koegel et al. 2002).

Parental Attributions

Another area of consideration could be how parents' beliefs or attributions about their children and treatment impact the outcome of the treatment. Preliminary research found an association between parent attributions that their children's behavior was stable (unlikely to change over time) and controllable (within the child's control) and lower ratings of the use ability of the strategies in the Stepping Stones program (Whittingham et al. 2009a). After participation in the treatment program, there was a significant change in parental attributions about misbehavior and ASD-related behavior. Parents were less likely to believe that misbehaviors were caused by internal factors specific to the child, and they were more likely to consider situational factors. This change is consistent with the behavioral-parenting strategies they were taught in the program. They were also less likely to believe that the ASD behaviors were enduring features of their children. The parents' attributions were not a significant predictor of change in behavior which suggests that it does not matter what the parents' beliefs were coming into the study.

Parental attributions that the child's misbehavior was due to internal factors before the study predicted the greatest change in parent's overreactivity (Whittingham et al. 2009a). Also, the more the parents attributed the behavior to temporary factors before the study, the greater the decrease in parents' overreactivity. The more the parent attributed control of behavior to the child, the greater the change in the parents' verbosity. This may indicate that these parents were engaging in the most lecturing and verbal explanations before the study and they had the most to learn from the program.

Although many parents had attributions before the study that contradicted behavioral strategies, the training was able to change the attributions and promote success and engagement in the program (Whittingham et al. 2009a). This should be encouraging information to clinicians who conduct parent training, given that it can be very discouraging to initially hear a family blaming their child or saying that they do not believe they will be able to use the strategies you will be teaching them. This study demonstrated that the teaching mechanisms in the Stepping Stones Triple P program were effective at changing the parents' beliefs which likely led to more effective use of the behavioral techniques. If anything, the parents with the most inaccurate beliefs showed the most change at the end of the training.

Cultural Considerations

Santarelli et al. (2001) have discussed the importance of considering cultural values and beliefs when creating and providing parent education services. The majority of research regarding parent training programs has been conducted with European White families and the values of other cultures may differ from those of the European White background. The authors point out several areas of concern that need to be considered when providing parent training to families of diverse ethnicities such as language barriers, the family's perception of "disability," the amount of support available from extended family, whether there is a sense of need for services, socioeconomic status, possible lack of transportation, and the clinicians own biases and beliefs.

The amount of social support and a lack of need for services is an interesting topic given the empirical support for the role of early intervention in prognosis (Dawson and Osterling 1997). Parents from cultures in which the seeking of outside support is discouraged may feel defeated when they do seek out services, or they may wait until the child is much older. One important point that the Santarelli et al. (2001) point out is that many insurance companies refuse to pay for parent education and parents sometimes have to fight to access services. If families view insurance companies as the "authority figures" they may not continue to seek out services.

A final potential barrier is the inclusion of all family members. If there are extended family members in the home or consistently involved in care, it will be important for parent training programs to provide instruction to all caregivers or at least adequate material for the involved parent to provide the instruction. Santarelli et al. (2001) emphasize the importance of involving the family in the goal-setting process in order to insure their cooperation with the plan. It is also important for clinicians to become familiar with the cultures that they are servicing, and if needed, obtain supervision from someone who has experience working with that culture

Father Involvement

The value of family involvement brings about another important factor to consider in the parent training literature: The majority of parenting training research studies have focused exclusively on mothers as trainees. This is most likely a result of more mothers being the full-time caregivers for children. However, an area of interest in the field of parenting training has been whether fathers can also be effective parent therapists for their children.

Many fathers express that they do not know how to play with their children when the children have limited verbal and social skills (Seung et al. 2006). Several small-scale studies have examined in-home training with fathers. Seung et al. (2006) specifically examined how fathers performed after being trained in expectant waiting and imitating with animation. The fathers were trained in the techniques and then encouraged to teach the mothers the skills as well. The authors found that both expectant waiting and imitating with animation were effective at increasing the number of child utterances and that fathers showed no difference in their learning of the skills as compared to mothers. When the data for each child were examined individually, it was found that children produced more words with their fathers during the maintenance phase than with their mothers.

In a more recent study, Elder et al. (2011) had fathers participate in parent training that taught imitation with animation, expectant waiting, commenting on the child, and following the child's lead. The fathers were then instructed to teach the children's mothers the same skills. Twelve weeks following the training, results demonstrated increases in fathers' use of commenting on child, expectant waiting, and imitation with animation. Child-initiating vocalizations and nonspeech vocalizations increased and mothers increased in the frequency of using imitation with animation, expectant waiting, and following the child's lead. Children's data were similar for both mothers and fathers.

In another study of culturally diverse fathers who were taught expectant waiting and imitating with animation, fathers reported that they did not know how to play or communicate with their child with ASD, and that this was very frustrating for them (Elder et al. 2003). Results indicated that imitating with animation did not occur naturally between these fathers and their children. The fathers were able to learn and utilize this skill, but they had difficulty learning expectant waiting. This may have been due to a natural response of fathers to direct their children. It was suggested that the ability to observe their children may be a needed skill for fathers before a more balanced relationship can occur between the father and child. The authors suggest that research should focus on ways to teach and measure this skill and find ways to increase it in fathers. It was also suggested that research should find ways to increase fathers' confidence and competence. This is an important suggestion given that there is some evidence that interventions designed to increase mothers' self-efficacy were not effective with fathers (Sofronoff and Farbotko 2002). In that study, it was suggested that a different focus may be needed when working with fathers that would increase interactions with children outside of behavior management. Fathers may be more able to engage in building a supportive relationship that involves different play and interests.

Flippin and Crais (2011) advocate for the inclusion of fathers in the research of parent training and adaptations of programs as needed to promote more involvement of fathers in treatment. Fathers may be able to make a unique contribution in regards to language development and play skills as fathers tend to have different interactions with their children than mothers. Involvement of fathers may also decrease the burden placed on mothers to learn all of the skills in parent training programs and possibly then decrease their stress levels. This idea is appealing given the high rate of stress that is reported by mothers of children with ASD and how previous research has demonstrated that high stress levels can impact how useful the parent training is to the family.

Early research suggested that fathers only engaged in the formal behavioral strategies when the mothers were also actively using them (Harris 1986). It was concluded at that time that it may be more important to train mothers as they may set the tone for maintenance of interventions in the home. The fathers who did use the formal techniques viewed their children's future as more positive. Although the early research supported training mothers first, cultural changes since the research was completed such as fathers becoming more involved in their children's care and lives may impact the validity of these results today. In a review of the literature concerning father involvement in parent training, Flippin and Crais (2011) found very few studies that included or reported results concerning fathers. These authors suggest adapting programs to be more father-friendly such as offering services later in the day to accommodate work schedules, presenting information in a fact-based manner, utilizing task-oriented learning, adding hands-on physical activity, and providing feedback on use of techniques.

Factors to Consider in Choosing a Parent Training Program

Prelock et al. (2011) provided several insights into parent training after conducting two pilot studies to increase joint attention, one of which trained new providers to implement parent training methods. The interventionists in the study emphasized the importance of parents choices in regards to treatment approaches, even when the parent's choice may not be the interventionists own choice. Parent buy-in may be the deciding factor between a treatment being effective or not, given they will be the ones eventually implementing it. This does not mean that a clinician should allow a family to blindly choose an intervention, but instead provide them education about the available interventions such as the expectations for training, the possible benefits, and the research support for each option. Prelock et al. (2011) also recommended that interventionists be taught flexibility and problem-solving strategies for when parent training methods do not go as planned. The clinicians involved in the study suggested there could be possible benefits of including both parents in the training such as creating a built-in support system for both parents and allowing the parents to learn from each other. Families in the study also shared how important it was to them to be

Table 28.1 Factors to consider in selecting treatment

Parent and Family Characteristics
Level of parental stress
Family Composition (e.g., single parent, number and age of other children)
Ability to pay for services (e.g., insurance coverage)
Amount of time available to provide direct services
Ability to travel to services
Availability of other social support for family
Need for general psychoeducation on ASD
Parent's preferences
Cultural considerations
Ability to understand and implement the interventions
Presence of own mental health issues
Child Characteristics
Age of the child
Specific areas of difficulty
Child's relationship with and responsiveness to the parent
Presence and severity of behavior problems
Ability to interact with other children in a group format
Other services the child is receiving concurrently (e.g., school services, private therapies, one-on-one interventions)
Availability of Services
Number and type of ASD-related services in the area (e.g., in-home services, center based)
Availability of support groups and general psychoeducation on ASD
Availability of providers to work with individual families
Cost of services and payment options (e.g., provider accepts insurance, payment plans)

connected to other families experiencing the same challenges.

When counseling a family on the treatment options available, there are a number of factors that the clinician should keep in mind. Table 28.1 presents a review of the factors discussed throughout this chapter that contribute to the decision-making process. These factors include parental stress, socioeconomic status, distance from services, age of the child, severity of the behavior problems, and parental time available to commit to the program. With so many factors to consider, it is vital that a conversation (or several) take place between the clinician and the parents in those early phases of treatment planning.

Summary

Parent training programs have been demonstrated to be effective in addressing many areas of difficulty experienced by children with ASD. These methodologies have also been effective in teaching general behavioral interventions as part of comprehensive treatment packages. The field of parenting training is primarily dominated by ABA strategies and the majority of the available research has involved ABA techniques. PRT is one form of parent training that has repeatedly demonstrated effectiveness in training parents to provide therapy to their children with ASD (Coolican et al. 2010; Harris 1986; Minjarez et al. 2011). Other options such as group-based and short-term interventions show promise in research, but more studies are needed.

Despite these positive findings, there are still areas that need to be addressed in the field of parent training with families of children with ASD. Several limitations exist in the research methodology utilized to date to study parent training. Many of the parent training studies currently available are short term in nature and longer outcomes need to be examined (McConachie and Diggle 2007). Another methodological issue is that research has been primarily conducted using pre- and posttest or single subject designs. There is a need for more RCTs that compare structured parent training with control groups. This is particularly important given the significant amount of time and money both families and providers are likely to devote to parent training programs, and not all programs have demonstrated effectiveness in RCT studies (Oosterling et al. 2010).

Future directions for research in this area include parent training programs that specifically address significant behavior problems. Many studies reviewed in this chapter excluded children with significant behavior problems, which is unfortunate considering that children with ASD can exhibit many behavioral difficulties. Failure to study the role of parent training in treating severe behavior problems seems to be missing one of the most crucial clinical concerns for this population. Another area for future research is the investigation of formal, standardized treatment packages as are few currently available (Matson et al. 2009). Standardized parent training programs that can be replicated in natural settings may be a beneficial focus in this area. This is particularly true for older children, given that many comprehensive programs focus on early intervention with young children. As children with ASD develop, their needs change and the skills parents need to manage them will therefore also change. Strategies for successful behavior change with a preschooler may be very different than those needed for a teenager. Use of standardized programs and focus on older individuals with ASD would be large contributions to the existing literature.

Another area for future examination includes the use of booster sessions. Many studies indicated that families felt that they needed additional assistance following the completion of the program (Mudford et al. 2001). Additional support from the school system in implementing behavioral strategies has been indicated in increasing the likelihood that parents will continue to use strategies they had learned in training, suggesting that parents may need encouragement to continue using their training (Harris 1986). Booster sessions may provide the support and encouragement families need in order to continue to use the strategies they learned during active treatment. Additionally, booster sessions may also be helpful in addressing new behavior problems that may emerge after training. More research is needed to determine the effectiveness of booster sessions in supporting families following a formal parent training program.

Finally, researchers have demonstrated that parental confidence in implementing the skills they learn can be influential in whether parents continue using strategies post training (Perry and Condillac 2010). Further understanding of the role of parent confidence and strategies to increase it during training is necessary. Self-efficacy in parents has been demonstrated to increase during parent training programs and parents who were more confident in their parenting skills and their ability to help their child were more likely to participate in and consistently implement interventions (Baharav and Reiser 2010). In fact, the more confident parents felt in their skills, the more they saw the intervention as being effective. Booster sessions may be a way to continue encouraging parents and address confidence levels post training.

In closing, parent training programs appear to be effective treatment options for individuals with ASD, and it is important for both practitioners and students to be aware of the research supporting parent training and the variety of methods available. Family characteristics and the different treatment options need to be considered in order to determine the best program for each family. Future research into the effects of treatment format, duration, and structure will hopefully only increase the support for the role of parents in addressing the social, communication, and behavioral difficulties seen in children with ASD.

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Multicultural and Minority Issues

29

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Keywords

Cross-cultural · Multi-cultural

Autism spectrum disorder (ASD) is one of the most prevalent neurodevelopmental disorders (Newschaffer et al. 2007). More children are diagnosed with ASD than with pediatric AIDS, juvenile diabetes, and childhood cancer combined (Center for Disease Control and Prevention (CDC) 2012). The core features of ASD include social skill impairment, communication deficits, and repetitive and restrictive behaviors (Fodstad et al. (2009); Matson and Boisjoli (2007); Matson et al. (2008); Matson and Wilkins (2008)). Although ASD has long been considered a "universal" disorder, affecting people of all ethnic, racial, and socioeconomic backgrounds, most research conducted in the past 60 years has considered primarily Caucasian samples (Dyches et al. (2004); Sun and Allison (2010)). This trend in sampling means that prior research findings are not necessarily generalizable to populations that have developmental disabilities and are from other cultural backgrounds.

Culture impacts various facets of psychopathology. Cross-cultural differences influence how people with mental disorders are perceived and treated (Snowden 2003). Ethnic-cultural factors influence the assessed, the assessor, and the relationship between the two (Tseng 1997), introducing variables previously unnecessary to consider before research became cross culture. As of now, the impact of culture on various aspects of ASD in particular has not been widely examined. Thus the purpose of this chapter is to review cross-cultural studies in order to better understand the influence of culture on the diagnosis, assessment, and treatment of individuals with ASD.

Cross-Cultural Differences in Prevalence Factors

There are numerous factors, specific to each culture, that affect prevalence of a disorder; such elements include but are not limited to biology, acceptance of the disorder within the community, and availability of support and services (Tseng 1997). Regarding ASD in particular, each of these aspects could potentially influence documented rates of occurrence. Disparities in genetic attributes, perception of developmental disorders and understanding of symptoms, and access to appropriate assessment services across cultures

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may influence apparent rates of ASD diagnoses. Changes in any of these factors among a culture could potentially result in subsequent decreases or increases of reported incidence of ASD.

Reported prevalence rates of ASD have dramatically increased in the past decade (Baron-Cohen et al. 2009; Chakrabarati and Fombonne 2001; Newschaffer et al. 2005). Research findings regarding the amount of increase remain discrepant; some researchers have reported that the rate of ASD has increased from 20 per 10,000 in the early 1990s (Wing 1993) to 60–70 per 10,000 in the early 2000s (Bertrand et al. 2001; Chakrabararti and Fombonne 2001). The most recent federal study reported that 1 in 88 children were diagnosed with ASD in the USA for the 2008 surveillance period (US; CDC 2012). Furthermore, the pattern of increased prevalence of ASD has been reported in most Western countries, including the UK (UK; Baird et al. 2000; Bertrand et al. 2001; Chakrabarti and Fombonne 2001; Webb et al. 2003), Sweden (Arvidsson et al. 1997; Gillberg et al. 2006), and Australia (Williams et al. 2008).

Although epidemiological studies of ASD in Asia are less common than in other regions, several research teams have reported a similar increase in ASD prevalence in Asian populations (Chien et al. 2011; Kim et al. 2011; Lin et al. 2011; Sun and Allison 2010). In many Asian countries, recent estimated ASD prevalence rates indicate 10–30 diagnoses of ASD per 10,000 people (Honda et al. 1996; Li et al. 2011; Wong and Hui 2008). However, discrepant prevalence rates have been reported as comparable to those in most Western countries (Kim et al. 2011). Furthermore, there is some evidence of an increase in prevalence of ASD in Asia over the past 20 years: Chien and colleagues (2011) reported that the ASD prevalence rate in Taiwan increased from 1.79 to 28.72 per 10,000 from 1996 to 2005, while Lin et al. (2011) found that ASD prevalence increased from 5 to 17.3 per 10,000 from 2000 to 2007. A recent review of ASD prevalence in Asian countries including China, Japan, Israel, Iran, Taiwan, and Indonesia indicated that the rate of ASD has increased from 1.9 per 10,000 in the 1980s to 14.8 per 10,000 since the 1980s (Sun and Allison 2010). Also, in the first population-based autism prevalence study in South Korea, researchers estimated the prevalence of ASD to be 1.89 % in the general population sample (Kim et al. 2011). Despite methodological differences across studies, evidence exists that supports an increase in ASD prevalence in Asia. In addition, ASD is reported to be more common than previously thought, potentially approaching prevalence found in Western countries.

Differences in the incidence of ASD across cultures should be noted. As aforementioned, the most recent prevalence study in the USA estimated that 1 in 88 children has ASD (CDC 2012). However, several research teams in the USA have concluded that this prevalence rate differs across cultural backgrounds. For example, ASD is reportedly less prevalent in Hispanic populations than Caucasian populations (CDC 2009). Additionally, in their review of evaluation records, Mandell and colleagues (2009) discovered in their adjusted analysis that children of African American, Hispanic, and other non-Caucasian ethnicities were less likely to have documentation of an ASD diagnosis than were Caucasian children. Other researchers reported that students in the US schools who were African American or Asian/Pacific Islanders were classified as having autism twice as often as their peers of American Indian/Alaskan or Hispanic background (Dyches et al. 2004). Furthermore, in his literature review, Dealberto (2011) concluded that prevalence of ASD was associated with maternal immigration status and ethnic origin.

Interestingly, Thomas and colleagues (2012) examined the relationship among rates of ASD diagnosis, cultural background, and socioeconomic status (SES) using data collected in NJ, USA. They noted there was no longer an association between rates of ASD diagnosis and cultural background after adjusting for median income, suggesting SES was the source of the discrepancy across cultures. Additionally, higher SES was associated with younger age at diagnosis (Thomas et al. 2012). These authors suggest several factors that could contribute to their findings: medical professionals responsible for the care of children in lower SES may have less training or time for diagnostic assessment, and parents with lower SES may not as readily identify abnormal development in their children. Additionally, Cuccaro and colleagues (1996) conducted a study in which they provided to various professionals vignettes that described a child with symptoms of either ASD or Attention-Deficit/Hyperactivity Disorder (ADHD). The vignettes also indicated the ethnic group membership or SES status of the child. The results of their analysis showed that professional perceptions were not influenced by ethnic group membership but did differ as a function of SES. Taken together, these findings suggest that differences in prevalence rates may be the consequences of differences in SES, rather than in culture.

In addition, other sociocultural factors such as increased public awareness, changes in diagnosis and referral patterns, and advances in assessment instruments may play a role in discrepant prevalence rates of ASD across cultures (Levy et al. 2009; Posserud et al. 2010). For example, some researchers have discovered a direct relationship between alterations in diagnostic criteria and resulting changes in prevalence rates in Australia (Nassar et al. 2009) and Denmark (Parner et al. 2011). A recent cross-ethnicity study conducted in the USA reported highest prevalence rates among Caucasian children and lowest rates in children of Hispanic descent, but methodological and sociocultural factors seemed to be largely responsible for the observed differences (Zaroff and Uhm 2012). Furthermore, there has been burgeoning evidence that ASD is a neurological disorder (National Research Council 2001). Researchers have demonstrated chromosome abnormalities and gene variants among persons with ASD (Christian et al. 2008; Marshall et al. 2008; Persico and Bourgeron 2006; Szatmari et al. 2007). Given these findings together, it is likely that various cultural factors do significantly influence on prevalence of ASD. Given the emerging understanding of the etiology of ASD, it is likely that differences in ASD prevalence across cultures are a result of numerous factors, sociocultural and otherwise.

Cross-Cultural Differences in ASD Symptoms

Although differences in ASD symptomatology across cultures are less frequently investigated than prevalence rates, this topic is an important one to consider. The lack of recent research on this topic may be due to predominant past evidence suggesting there is little variation in the behavioral manifestation of ASD across culture, ethnicity, and social class (Campbell 1996; Cuccaro et al. 1996; Morgan 1996). In addition, more recent research found similarities in age of ASD onset, core symptomatology, and prevalence across European and North American populations (Fombonne 2009). Nonetheless, a consensus regarding degree of difference in ASD symptomatology across cultures has not yet been established due to recent discrepancies in results. Overall, potential differences in symptom frequency, severity, and presentation across cultures is considered less frequently than other topics related to the relationship between culture and ASD. Thus, further investigation of this topic is necessary to clarify discrepant findings.

Differences in ASD symptoms across cultures have been discovered in the past. For instance, in his comparison of direct observations of African and British children, Lotter (1978) found that African children displayed fewer repetitive movements (e.g., flapping, rocking) and complex ritualistic activities, but more repetitive manipulation of objects (e.g., carrying or banging items) than their British counterparts. Although the author noted that he used a screening checklist, little additional information is available about his observation procedure, and thus results should be interpreted with caution.

In one of the latest studies investigating this topic, Horovitz and colleagues (2011) found no significant differences between Caucasian Americans and African Americans on the *Baby and Infant Screen for Children with Autism Traits: Part 3* (BISCUIT-Part 3; Matson et al. 2007) in caregiver ratings of three items addressing stereotypic behavior (Horovitz et al. 2011). Additionally, other researchers in the USA (Chaidez et al. 2012) examined several characteristics of

Hispanic and non-Hispanic participants and found no significant differences in any subscale of the *Autism Diagnostic Interview, Revised* (ADI-R; Lord et al. 1994; Rutter et al. 2003), a widely used caregiver report measure of ASD symptoms. Further, acculturation did not appear to have an effect on symptom severity (Chaidez et al. 2012). However, it is important to note that these authors did not use a standardized measure of acculturation, but rather used country of birth and age at immigration as a proxy.

Recently, a group of researchers evaluated the impact of cross-cultural factors on endorsed ASD symptoms (Matson et al. 2011; Zachor et al. 2011), challenging behaviors (Chung et al. 2012), and social skills behaviors (Matson et al. 2012) in four different countries: the USA, the UK, Israel, and South Korea. The authors used several standardized informant report measures: they assessed symptoms of ASD using the *Autism Spectrum Disorders-Diagnostic for Children* (ASD-DC; Matson and Gonzalez 2007c), challenging behaviors using the *Autism Spectrum Disorders-Behavior Problems for Children* (ASD-PBC; Matson and Gonzalez 2007a), comorbid symptoms using the *Autism Spectrum Disorders-Comorbidity Child Version* (ASD-CC; Matson and Gonzalez 2007b), and social skills using the *Matson Evaluation of Social Skills with Youngsters-II* (MESSY-II; Matson 2010).

First, Matson and colleagues (2011) examined symptoms of ASD in children from different cultures to evaluate the effect these differences would have on the diagnosis of ASD. They reported significant differences across cultures for all core ASD symptom domains (i.e., nonverbal communication/socialization, verbal communication, and insistence upon sameness/restricted interests). For example, participants from the UK showed significantly more impairment across all domains, and children from Israel showed significantly less impairment. However, no significant differences emerged between participants on the domain of social relationships. Zachor and colleagues (2011) examined cross-cultural differences in comorbid symptoms of children with ASD. They found that participants from the USA had significantly higher scores than participants from South Korea on the avoidant subscale. Additionally, participants from the USA had significantly higher scores than participants from Israel on the overeating and tantrum subscales. No significant differences were found between children from the USA and children from the UK. In a similar study, Chung and colleagues (2012) compared children from the same countries on the presence and severity of challenging behaviors that are often exhibited by individuals with ASD. The authors found that, compared to the participants from South Korea and Israel, those from the USA did not differ on many challenging behaviors but did exhibit higher levels of externalizing behaviors. On the other hand, the participants from the UK had significantly higher endorsements of presence and severity of challenging behaviors than the participants from the USA on approximately half of the challenging behaviors examined. Lastly, Matson et al. (2012) examined the differences in reported symptoms of appropriate and inappropriate social skills between children and adolescents from South Korea and the USA using the *MESSY-II*. Although participants from the two countries scored statistically different from each other on all three subscales (e.g., Hostile, Adaptive/Appropriate, and Inappropriately Assertive), the mean scores fell into the same impairment level, indicating no clinically significant differences.

All of the aforementioned more recent studies used informant report measures to assess the occurrence of ASD symptoms. This is somewhat problematic because symptom perception, recognition, and interpretation appear to differ across cultures (Rogers-Adkinson et al. 2003). Therefore, perhaps a better way to investigate this topic would be to use a standardized observation measure to assess the behavior of children of different cultural backgrounds. Nonetheless, even standardized observations are influenced by the administrator's perceptions and biases, which can impact assessment results, as elaborated on in the following section.

Cross-Cultural Differences in Perception of ASD Symptoms

As discussed, further analysis is necessary regarding behavioral manifestations of ASD across cultures, as it is difficult to make solid conclusions based on the research presently available. An additional aspect to consider when examining ASD symptomatology across cultures is its influence on perception of symptoms. The potential impact of the cultural background of the child, of the caregiver serving as an interview informant, and of the clinician interpreting informant report and making personal observations are important to take into account. For instance, the cultural awareness and sensitivity of the clinician, as well as his or her culturally based value system, can have an effect on his or her assessment and interpretation of presenting symptoms (Tseng 1997). Furthermore, because research procedure for symptom assessment frequently consists of interview measures, the influence of informant biases are also important to consider. There are significant differences in terms of symptom perception, recognition, and interpretation (Rogers-Adkinson et al. 2003), report style (Daley 2002), and acceptance of diagnosis of ASD (Dyches et al. 2004) across cultures.

Mandell et al. (2007) determined that, in their sample of 406 Medicaid-eligible children, Caucasian children were almost three times more likely than their African American counterparts to receive an autism diagnosis on their first visit to a specialty care provider. This pattern may result in to an apparent difference in age of onset; researchers in the USA reported that children of Hispanic and African American backgrounds, as well as those born to foreign mothers, were diagnosed later than their Caucasian peers (Valicenti-McDermott et al. 2012). This is a problematic trend; if, for minority populations, appropriate diagnoses necessitate more time dedicated to assessment, valuable time is lost that could be used for early intervention and effective treatment techniques.

Furthermore, different cultural expectations of typical development may influence identification of symptoms characteristic of ASD and the time of diagnosis (Daley 2002), as well as impact the consideration of behaviors as developmentally normal or abnormal. For example, parents in different cultures (e.g., Australian and Lebanese mothers living in Australia; Goodnow et al. 1984) may have discrepant expectations regarding the timetable for various developmental milestones. As a result, a child may be considered developmentally delayed in one culture but “on track” in another. Such a disparity could influence age at referral to a clinician and subsequent diagnosis.

Additionally, there may be differences across cultures in the use of pointing, eye contact, sarcasm, physical touch, personal space, voice inflection, and gestures (Dyches 2011). Thus, identification of dysfunction in such facets of behavior likely differs across cultures, meaning lack thereof may not necessarily be considered problematic or symptomatic of ASD. For instance, in rural South Africa, should a child look directly into an adult’s eyes while conversing, the adult would consider it disrespectful (DeWeerdt 2012). However, a lack of eye contact is a common indication, even a hallmark, of ASD symptomatology. Without cultural consideration, the presence or absence of a behavior as a manifestation of cultural values could be interpreted as problematic, even indicative of disorder.

Furthermore, difficulties perceived as communication deficits could actually be manifestations of a language barrier (Begeer et al. 2009). This misperception is likely more common among immigrant children or those living in households where the predominant language spoken is different than the language spoken by the majority culture. In such situations, the children’s learning of the language in which the diagnostic assessment is conducted may be delayed, which could subsequently be misinterpreted as communication difficulties attributable to ASD.

Perspectives regarding etiology or causes of ASD also vary substantially across cultures and can impact a family’s reaction to a diagnosis. For instance, some young Hispanic mothers view parenting a child with a developmental disability as a challenge to improve character, while their elders may perceive it as a punishment for a sin the parents committed (Skinner et al. 1999).

Similarly, Asian parents may attribute disability to supernatural forces or the sins of the child's ancestors (Chan 1992). Among African American families, having close ties to a church or religion appears to play an important role in the positive appraisals of rearing a child with disabilities (Glidden et al. 1999).

Differences across cultures in the perception of symptoms and appraisal of having a child with ASD are important to consider for several reasons. Primarily, the way in which a parent interprets his or her child's behavior influences not only the type of treatment sought, but also affects a more crucial decision, whether or not to seek treatment at all (Mandell and Novak 2005).

Furthermore, caregiver appraisals affect perception of the burden of caring for a child with ASD, which in turn affects levels of parental stress. For instance, a negative appraisal of caring for a child with ASD in turn increases perception of burden (Stuart and McGrew 2009).

Cross-Cultural Differences in Treatment

Since Lovaas's treatment study in 1987, which reported results of behavior modification treatment for autism, there has been a dramatic increase in outcome studies, as well as significant changes in the mental health service system in the USA. Particularly, applied behavior analysis (ABA) became a treatment option based upon research conducted in the past 30 years. Several divisions under the American Psychological Association (APA) declared ABA as evidence-based treatment for autism (i.e., Division 33, Division 55; APA, 2012). In addition, federal government agencies such as the National Research Council and National Institute of Mental Health, as well as state governments including those of New York, Washington, and Maine, recommend ABA as an effective teaching method for ASD. As a result, diverse types of ABA services are provided via school districts or private agencies, though the nature of services differs across states.

Although the current status of treatment knowledge and service is significantly better in the USA than in many other countries, utilization of treatment differs across Americans of varying cultural backgrounds. In particular, researchers have indicated that minority cultures in the USA seek psychological services less frequently than Caucasians, and more frequently turn to primary care providers or informal sources (see review by Satcher 2001).

One major obstacle to receiving services among minority cultures in the USA is the language barrier between service provider and client and/or family. For example, Choi and Wynne (2000) conducted a survey of use of mainstream services among Asian Americans to determine common obstacles. These authors cite communication difficulties between families and service providers as a major discouraging factor in Asian American families seeking formal services. Information on developmental disabilities is not always available in all languages spoken by families necessitating services. In fact, there is not even a word for *autism* in some Asian languages (Wilder et al. 2004).

Values specific to certain cultures may also influence treatment perception and utilization. For example, Choi and Wynne (2000) suggested that the strong emphasis on privacy among Asian Americans discourages seeking of assessment services, in which families may have to delve into personal histories and other sensitive matters, as well as decreased participation in support groups, in which sharing personal experiences is central. Without receipt of mainstream services, these families may turn to alternative methods, such as acupuncture and herbs, that are traditional in their culture and therefore better reflect their values. Additionally, African Americans place great importance on the opinions of family, friends, and religious groups, and thus are prone to turn to these individuals before seeking services (Snowden 2001). This preference likely contributes to the decreased seeking of mental health services among African Americans compared to Caucasian Americans.

Information about effective treatment and available service provided by government and private agencies are very limited in many countries, including Ireland, Germany, Italy, China, Taiwan, and South Korea (Chung et al. 2012; Eikeseth et al. 2007; Keenan et al. 2010; Lin et al. 2011; Reed et al. 2007; Yangqing 2006). Although the prevalence of autism appears to be increasing, services have not necessarily followed suit. Existing government support and assistance for affected children and their families remains insufficient. ABA services are extremely limited due to lack of training and educational programs. By nature, ABA services require intensive treatment hours, systematic treatment plans with frequent modifications, trained and dedicated staffs, and financial support. Hence, this type of service is difficult to sustain without a systematic treatment service system in place in the community and/or government. In communities lacking such a system, the burden of treating and educating children with autism falls primarily on caregivers.

In China, autism treatment techniques range from using herbs and acupuncture (e.g., Wong 2002; Zhang 1988) to sensory integration training (e.g., Lin and Zhang 1995; Wang 2000). ABA is provided in rare cases. Clark and Zhou (2005) discussed that psychiatric hospitals offer limited treatment which focus only on improving motor skills. "Stars and Rain" is one of the few programs that uses behavioral principles to treat children with autism; however, the treatment cost is not feasible for most families. Currently, there are no public school programs designed to effectively address the needs of children with ASD; available services are not intensive nor individualized enough (Clark and Zhou 2005).

Across Europe, ABA treatment funding is prevented. For example, the Irish government has fought against parents who requested ABA treatment for their children (Keenan et al. 2010). ABA services are funded only when ordered by a tribunal (i.e., judicial system) in the UK, and statutory ABA treatment is non-existent in Germany and Italy. In most cases, parents have to pay out of pocket if they want home-based behavioral programs (Keenan et al. 2010).

The current status of autism treatment in South Korea is not any better. Although principles of behavior modification were introduced in South Korea in the early 1980s, it was not until the past 10 years that ABA has started to receive acknowledgement from the general population as a treatment choice for ASD. There are only a handful of ABA service providers in South Korea. This is not surprising considering the fact that there were only 13 Board Certified Behavior Analysts (BCBAs)/Board Certified assistant Behavior Analysts (BCaBAs) in South Korea as of Jan., 2014 (http://www.bacb.com). The majority of South Korean children with ASD receive other, likely better known, types of interventions, including play therapy, speech/language therapy, music, dance and art therapy, etc. Some parents seek other controversial treatments such as auditory integration therapy (AIT), gluten/casein free diet, animal therapy, etc.

A brief review of treatment outcome studies for children with ASD in South Korean instructional settings was conducted for the purpose of this book chapter. The 3 most reputable Korean databases (e.g., KISS, DBia, RISS) were used. A total number of 262 studies were found using a combination of the following terms: *autism*, *pervasive developmental disorders*, *developmental disabilities*, *treatment*, and *therapy*. Studies were categorized based on treatment methods: art therapy (36 %), music therapy (29 %), play therapy (21 %), dance/movement therapy (5 %), ABA (5 %), etc. Results demonstrated the current status of treatment practice and research in South Korea, which is far from optimal. Recently, the Korean Society for Child and Adolescent Psychiatry published treatment recommendations for ASD (Koo et al. 2007). This is the first formal ASD treatment guideline by professionals in South Korea. Although ABA is recommended along with understudied and not-yet proven methods, the development of treatment guideline is a meaningful step toward dissemination of evidence-based ASD treatment in South Korea.

Thanks to recent economic growth along with increased awareness of ASD, more structural and systematic supports have been available for families of children with ASD in South Korea. In fact, the Act on the Promotion of Education for the Handicapped (APEH), the law ensuring service provision for children with disabilities, was revisited in 2007. The regulations under the revised and enlarged APEH are fairly similar to the Individuals with Disabilities Education Improvement Act of 2004 (IDEA 2004), except that imited systematic and financial supports are currently available in South Korea. Advocacy by active parent support groups may help progress service provision in upcoming years. Nonetheless, at present, current services are minimal, limited to assistance such as respite care, vouchers for limited-time treatment, and food stamps. Currently, parents are responsible for all costs associated with additional treatment and related services. According to a recent survey in South Korea, approximately 78 % of parents of children with ASD spend more than US$ 1000 per month for treatment (Lee et al. 2010). Considering that the 2012 Gross Domestic Product (GDP) in South Korea was approximately US $ 23,000 (http://www.imf.org/external/data.htm), it can be assumed that treatment cost is a substantial burden to families.

There are a few ABA clinics in South Korea; In 2007, the a city hospital for children in Korea opened an ABA clinic specializing in severe challenging behavior, benchmarking the Neurobehavior Unit Outpatient Clinic (UBU-OP) in the Department of Behavior Psychology at the Kennedy Krieger Institute. Seoul Metropolitan Children's Hospital has provided assessment and treatment services, including parent training, workshops, and social skills training, to more than 200 children and adolescents. The program is significantly less expensive than other existing services but still places a financial burden on the family, with companies rarely helping their employees with costs of services for ASD. Due to an insufficient number of trained therapists, the waiting list is several years. Diverse efforts have been made to resolve this issue, but no drastic changes are expected in the near future. However, other promising progress has been made in this setting with expansion of ABA services in the form of an early intervention and feeding clinic opened in 2011. The clinic is based on programs from various US agencies (e.g., New England Center for Children, Center for Autism and Related Disorder, Denver Early Intervention Program), as well as commercial programs (e.g., STAR program).

The biggest obstacle to providing quality ABA services in South Korea is limited education and training programs for therapists. There are only 3 BACB (Behavior Analyst Certification Board) accredited programs in Korea. Additionally, new hiring is not guaranteed due to lack of ABA clinics and average annual salary for a therapist is less than $ 20,000, making recruiting therapists extremely difficult. Currently, many therapists in the city hospital are either BCBA/BCaBA certified or under training to be certified. The therapists take internet courses via the US institutions to meet the requirements for the certification exam. Using these US programs means the trainees must overcome the language barrier, which has proven a big obstacle with multiple certification exam attempts (i.e., average of four attempts) necessary before successful completion.

In July 2012, the South Korean Department of Health announced a new plan for persons with developmental disorders, including ASD, which includes system development and support for diagnosis and early intervention for children (http://english.mw.go.kr/front_eng/index.jsp). In 2013, they oped an ABA clinic for challenging behaviors at the Seoul National Hospital, the biggest national psychiatric hospital in South Korea, for treatment of severe challenging behavior. Although there are potential barriers and issues to be resolved, this is truly significant system progress in the treatment of ASD for the country.

Cross-Cultural Factors to be Considered

Because parents have more contact with their children than other service providers, such as therapists or clinicians, effective parent training is an essential part of treatment for children with ASD. Previous studies have shown that parents can successfully implement behavioral procedures, which lead to beneficial outcomes (Reagon and Higbee 2009; Vismara et al. 2009). Thus, investigating cross-cultural differences in parental factors, such as parental reporting style, social support/coping, and stress, is necessary to better understand differences in ASD across cultures.

It is not surprising to see differences in ASD prevalence across countries, considering cross-cultural differences in parental perception of, beliefs about, and reporting styles regarding their children's symptoms. For example, Bornstein and colleagues (1998) compared parenting-related issues in Argentine, Belgian, French, Israeli, Italian, Japanese, and American mothers of 20-month-olds. Maternal competence, satisfaction, investment, and role balance in parenting, as well as attributions of successes and failures, were investigated. Mothers from different cultures shared few similarities in parenting ideas. In this study, US mothers rated themselves competent and satisfied in their parenting. On the other hand, Japanese mothers reported themselves to be the least competent or satisfied in their parenting. They were also more likely to attribute their children's accomplishments to parental efforts; when the child was not typically developing, the mother was considered not working hard enough as a parent. In this culture, under-detection or underreport of children's problems is common when a child is not typically developing. Indeed, underreporting of children's challenging behaviors has been found in several Asian countries (Chung et al. 2013; Oh et al. 2002).

The topic of cross-cultural differences in social support and coping skills among parents of children with ASD has not been frequently studied. Lin and colleagues (2011) compared social support and coping styles between Taiwanese and American mothers of children with ASD. No differences were found between the groups in terms of social support, but Taiwanese mothers reported using significantly more problem-focused and emotion-focused coping skills than American mothers did. More frequent use of emotion-focused coping skills among Taiwanese mothers could be attributed to lower levels of family adaptability and cohesion and lead to higher levels of maternal depressive symptoms. Furthermore, Chinese parents seem to avoid seeking social support from people outside the family when they have a child with intellectual and developmental disabilities (Holroyd 2003; Lam and Mackenzie 2002; Pearson and Chan 1993).

Parenting stress is defined as psychological distress arising from the demands of rearing children (Anthony et al. 2005; Reitman et al. 2002). Researchers have consistently confirmed distinct types of parenting stress across cultures (Krulik et al. 1999; Solis and Abidin 1991). For example, Krulik and colleagues (1999) found that Japanese mothers of chronically ill children showed more stress in role restriction and depression but less stress in terms of competency than mothers from the USA, Israel, and Jordan. Similarly, Solis and Abidin (1991) found that in a Hispanic sample, mothers of handicapped children reported more stress than those of non-handicapped children.

Children's challenging behaviors are one of the most powerful predictors of parenting stress (Baker et al. 2002; Baker et al. 2003; Harrison and Sofronoff 2002). Researchers in the USA have consistently found that parents of children with developmental delays including autism report higher levels of parenting stress compared to their normative counterparts (Baker et al. 2002; Baker et al. 2003). Outside of the USA, however, only a few studies have investigated this relationship between parenting stress and challenging behaviors in children. Chung and colleagues (2013) directly compared differences in reported parenting stress and childhood problem behaviors across Korean and American mothers. Korean mothers reported significantly higher parenting stress, yet significantly lower childhood challenging behaviors, compared to American mothers. In addition, mother-based reports of child problems were significantly associated with parenting stress in the American sample but not in the Korean sample.

Explanations for cross-cultural differences in parental factors are speculated but have not been thoroughly investigated. Cultural values appear to play an important role for this discrepancy. In China, having a child with a disability is viewed as a failure (Chen and Tang 1997; Ghosh and Magan 2009), so Chinese parents tend not to expose their child with a disability to the public and are reluctant to seek help from outside (Clark and Zhou 2005). Similarly, Confucian values, which are heavily ingrained in Korean society, have contributed to a sense of collectivism whereby “standing out” or being different is not encouraged. In such an environment, reporting that their child has a disability goes against this ideal, contributing to elevated levels of parenting stress and the reluctance to report such information. Currently, relatively low levels of social support exist in South Korea (Shin 2002). Given that social support serves as a preventative buffer against parenting stress (Crnic et al. 1983), this feature of Korean society may also contribute to heightened levels of parenting stress among Korean parents. Negative stigma related to having children with a disability is also very prevalent in South Korea (Cho et al. 2003). Together, these societal and cultural factors likely affect levels of parenting stress and willingness to report emotional and behavioral problems of their children among Korean parents.

Conclusion

The current chapter reviewed cross-cultural differences in ASD prevalence, behavioral manifestation, and treatment. It further provided several sociocultural factors as possible explanations for disparities. Research has yielded mixed results regarding discrepancies in autism prevalence across different cultures. Despite inconsistent findings, there appears to be a pattern of increasing rates of ASD diagnoses in non-Western countries. There have been varying reports of cross-cultural distinctions in ASD symptomology as well; there is some evidence of minimal variation in the behavioral manifestation of ASD across cultures, while other research indicate no differences. Dissimilarities in treatment across cultures were also discussed in terms of what options are available and chosen among various ethnicities and in certain countries. Overall, the current status of treatment knowledge and provision appears to be significantly better in the USA than many other countries.

Some experts attribute disparities in various factors concerning ASD (e.g., prevalence, symptomatology, treatment) to differing cultural practices, beliefs, and values. Such cultural aspects may influence perception of ASD, resulting in differences in assessment, and thus prevalence rates and ratings of symptomatology, as well as in treatment. Thus, the relationship between factors related to ASD and aspects of culture appears to be somewhat circular in nature. However, firm conclusions about this relationship and the topic of multicultural and minority issues in ASD in general cannot yet be made based on existing evidence. Most of the cross-cultural studies in this area have been conducted without systematic exploration of the factors underlying discovered differences across cultures. Therefore, only speculations about the source of cultural differences in ASD are available at this point. Although such ideas seem plausible and explanatory, they lack empirical evidence and thus are just possibilities that require further exploration. Future studies should aim to further understand reasons for cross-cultural differences in order to increase efficacy of assessment and treatment for affected people of all ethnic, racial, and backgrounds.

> Of course, research findings on this topic influence not only subsequent analyses, but also serve to inform clinical practice. From a clinical standpoint, cultural awareness and sensitivity development are important for a professional to appropriately serve a multicultural or minority population. With knowledge of culture’s influence on the various aspects of ASD discussed, clinicians will be better prepared and more likely to take the client’s cultural background into account during assessment and interpretation, resulting in more personalized and applicable outcomes and recommendations. Thus, additional research on this area of interest is warranted because further knowledge may encourage individual treatment, and thus optimal outcome for this population.

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