

Introduction

In 1943, Leo Kanner first described autism. This perplexing and highly enigmatic disorder is characterized by difficulty in interacting normally with others; speech, language, and communication impairments (e.g., delayed speech, echolalia); an insistence on environmental sameness; stereotypic and other self-stimulatory responses; and a variety of aberrant responses to sensory stimuli (American Psychiatric Association [APA], 2000; Klin, Volkmar, & Sparrow, 2000; Simpson & Myles, 1998). At the same time, however, it is not unusual for individuals with autism to have normal physical growth and development, and some children and youth with autism spectrum disorders (ASD) have splinter skills and other isolated and unique skills, knowledge, and abilities (Berkell Zager, 1999). Moreover, individuals with ASD have a wide range of abilities, ranging from near- or above-average intellectual and communication abilities to severe mental retardation and an absence of spoken language (Myles & Simpson, 2003).

The preferred current term for describing children and youth with autism-related disorders is *autism spectrum disorders (ASD)*. This term is used to refer to the broad range of subtypes and levels of severity that fall on the spectrum of autism and pervasive developmental disorders. Specific major diagnostic groups within the spectrum include autistic disorder, childhood disintegrative disorder, Rett disorder, Asperger syndrome, pervasive developmental disorders not otherwise specified, and atypical autism. There are other forms of autism and pervasive developmental disorders on the spectrum, but the aforementioned are the primary subgroups of autism.

DEFINITIONS OF AUTISM AND RELATED DISORDERS

Current commonly used definitions of autism include those contained in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-Text Revision* (DSM-IV-TR; American Psychiatric Association, 2000), the definition advanced by the Autism Society of America (2004), the definition of

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the International Classification of Diseases (World Health Organization [WHO], 1993), and the educational definition of autism adopted for use in the Individuals With Disabilities Education Act (IDEA) amendments of 1997. These definitions of autism are briefly presented here and are followed by definitions of the major diagnostic groups within ASD.

DSM-IV Definition of Autism

A widely used definition of autism is that of the DSM-IV-TR (APA, 2000), which classifies autism as a pervasive developmental disorder. Children and youth identified as having a pervasive developmental disorder “are characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities” (p. 69). These behavioral patterns are shown in the first few years of life and are significantly atypical for a child’s mental age or developmental level.

Autism Society of America Definition of Autism

Based on a conceptualization and definition originally developed by Ritvo and Freeman (1978), the Autism Society of America (2004) relies on the following definition of autism, which is closely aligned with the criteria used in the DSM-IV-TR (APA, 2000) and Kanner’s (1943) original observations of autism:

Autism is a complex developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects the functioning of the brain, autism and its associated behaviors have been estimated to occur in as many as 2 to 6 in 1,000 individuals (Centers for Disease Control and Prevention, 2001). Autism is four times more prevalent in boys than girls and knows no racial, ethnic, or social boundaries. Family income, lifestyle, and educational levels do not affect the chance of autism’s occurrence. (Autism Society of America, 2004)

According to the Autism Society of America, autism impacts the normal development of the brain in areas of social interaction and communication skills. Children and adults with autism typically have difficulties in verbal and nonverbal communication, social interactions, and leisure or play activities. The disorder makes it hard for them to communicate with others and relate to the outside world. In some cases, aggressive and/or self-injurious behavior may be present. Persons with autism

may exhibit repeated body movements (hand flapping, rocking), unusual responses to people or attachments to objects, and resistance to changes in routines. Individuals may also experience sensitivities in the five senses (sight, hearing, touch, smell, and taste).

The Autism Society of America estimates that 500,000 to 1,500,000 people in the United States today have autism or some form of pervasive developmental disorder. Its prevalence rate makes autism one of the most common developmental disabilities. Yet most of the public, including many professionals in the medical, educational, and vocational fields, are still unaware of how autism affects people and how they can effectively work with individuals with autism.

International Classification of Diseases, Tenth Revision: Definition of Autism Spectrum Disorders

The International Classification of Diseases, Tenth Revision (ICD-10; World Health Organization, 1993) uses the term *pervasive developmental disorders* to refer to ASD. With few exceptions, the ICD-10 classification system conceptualizes and defines autism in a manner similar to the DSM-IV-TR (APA, 2000). Thus, the ICD-10 classification system includes and defines the following autism spectrum disorders: childhood autism, Rett syndrome, other childhood disintegrative disorder, Asperger syndrome, other pervasive developmental disorders, pervasive developmental disorders—unspecified, overactive disorder with mental retardation with stereotyped movements, and atypical autism. The term *atypical autism* is used to refer to age, symptoms, or other characteristics of autism along with behavioral excess, such as self-stimulatory responses and other nonfunctional movements, and mental retardation.

Federal Definition of Autism

The Individuals With Disabilities Education Act of 1997 provides an educational operational definition of autism that, although similar to the aforementioned definitions of ASD, has unique elements:

Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change, or change in daily routines, and unusual responses to sensory experiences.

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The term does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance. A child who manifests the characteristics of autism after age 3 could be diagnosed as having "autism" if the criteria above are satisfied. (20 U.S.C. § 1400)

Autistic Disorder

In accordance with the DSM-IV-TR (APA, 2000) guidelines, the term *autistic disorder* applies to individuals who have social interaction impairments, communication impairments, and repetitive, stereotypic, and restricted interests and activities prior to 36 months of age. Most children diagnosed as having autistic disorder are moderately to severely impaired, having IQs that fall in the range of moderate to severe mental retardation. Specific DSM-IV-TR diagnostic criteria for autistic disorder are as follows:

1. Qualitative social interaction impairments as shown by at least two of the following characteristics:
 - Significant impairment in the use of nonverbal behaviors, including eye-to-eye contact, facial expression, body posture, and social interaction gestures
 - Inability to establish developmentally appropriate peer relationships
 - Failure to spontaneously seek opportunities to interact with other people (e.g., by a lack of identifying objects of interest)
 - Poor social or emotional reciprocity
2. Qualitative communication impairments as shown by at least one of the following characteristics:
 - Delay in, or total lack of, spoken language development (not accompanied by an attempt to use alternative modes of communication such as gestures)
 - Stereotyped and repetitive language use or idiosyncratic language
 - Lack of varied, developmentally appropriate spontaneous make-believe play or social imitative play
3. Repetitive and restricted stereotyped patterns of behavior, activities, and interests, as shown by at least one of these characteristics:
 - Marked preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in focus or in intensity

- Inflexible adherence to nonfunctional routines or rituals
- Stereotyped and repetitive motor movements, such as hand or finger flapping or twisting or complex whole-body movements
- Persistent preoccupation with objects or components

Childhood Disintegrative Disorder

According to the DSM-IV-TR (APA, 2000), children identified having childhood disintegrative disorder have behavior patterns similar to those of children with autistic disorder. The distinction between persons with childhood disintegrative disorder and those with autistic disorder relates to the age of disability onset. Children diagnosed with autistic disorder display characteristics of pervasive developmental disorder prior to 3 years of age. In contrast, children with childhood disintegrative disorder show a period of normal growth and development prior to showing social interaction, communication, and behavioral impairments. That is, after showing at least two years of apparently normal development but before 10 years of age, children diagnosed as having childhood disintegrative disorder display “a clinically significant loss of previously acquired social skills or adaptive behavior, bowel or bladder control, play or motor skills” (APA, 2000, p. 77).

Rett Disorder

According to the DSM-IV-TR (APA, 2000), Rett disorder is a relatively rare condition that occurs only in females. Onset of the disability typically occurs between the ages of 1 and 2 and is characterized by head growth deceleration, loss of previously acquired hand movements and other motor skills, stereotypic hand wringing or hand washing, various motor impairments, and social and communicative impairments. Loss of previously acquired skills tends to be progressive and permanent, and prognosis (i.e., prediction about the course and outcome of the disorder) for individuals with Rett disorder is poor.

Asperger Syndrome

Impairments in social interaction are the primary characteristic of individuals with Asperger syndrome. Asperger syndrome is named after the German physician Hans Asperger, who in 1944 identified a group of high-functioning children with autism-related symptoms. Asperger syndrome was generally ignored in the United States until the 1990s. Today, however, there has been an enormous increase in interest in the work of Asperger and in Asperger syndrome. This renewed interest has at least in part been related to the expansion of the autism spectrum to include

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individuals with autism-type symptoms who are able to function at a relatively high level.

Frith (1991) observed that children with Asperger syndrome “tend to speak fluently by the time they are five, even if their language development was slow to begin with, and even if their language is noticeably odd in its use for communication” (p. 3). Frith further observed that “as they grow older they often become quite interested in other people and thus belie the stereotype of the aloof and withdrawn autistic child. Nevertheless, they remain socially inept in their approaches and interactions” (pp. 3–4). Although the exact prevalence of Asperger syndrome is unknown, it appears to be a relatively common form of ASD. In this regard, many schools are reporting significant numbers of students with this diagnosis (Klin et al., 2000; Myles & Simpson, 2003). DSM-IV-TR (APA, 2000) diagnostic criteria for Asperger syndrome are summarized as follows:

1. Qualitative social interaction impairment as shown by at least two of the following characteristics:
 - Marked impairment in the use of nonverbal behaviors, including eye-to-eye contact, facial expressions, body postures, and social interaction
 - Failure to spontaneously seek opportunities and interact with other people (e.g., by a lack of identifying objects of interest)
 - Poor social or emotional reciprocity
2. Repetitive and restricted stereotyped patterns of behavior, activities, and interests, as shown by at least one of the following characteristics:
 - Marked preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in focus or in intensity
 - Inflexible adherence to nonfunctional routines or rituals
 - Stereotyped and repetitive motor movements, such as hand or finger flapping or twisting or complex whole body movements

Pervasive Developmental Disorder—Not Otherwise Specified

Pervasive developmental disorder—not otherwise specified (PDD-NOS) is a somewhat vaguely defined diagnostic classification that refers to children who manifest “severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills” (APA, 1994, p. 77). The criteria for other forms of pervasive developmental disorder or other disabilities are not met, and

children with PDD-NOS generally fall at the higher functioning end of the autism continuum.

INTERVENTIONS AND TREATMENTS FOR CHILDREN AND YOUTH WITH AUTISM SPECTRUM DISORDERS

Related to ASD, this resource presents an overview and analysis of currently available interventions and treatments for children, youth, and adults with ASD. Thus, this book briefly evaluates the utility and efficiency of commonly used and purported interventions and treatments for individuals with autism-related disabilities.

The inspiration for this work is a direct function of the extraordinary difficulty that professionals, parents, and family members encounter in selecting and applying appropriate and efficacious interventions and treatments with individuals with ASD. Indeed, there are countless interventions and treatments that purport to be suitable for individuals with ASD, a number of which either have not been scientifically validated or have been determined to have little or no worth. That ASD is such a perplexing and enigmatic disorder only adds to the difficulty of selecting and applying maximally effective treatments and interventions.

It is often difficult for parents and professionals to recognize and judge the scientific validity of an intervention or treatment designed to be used with individuals with ASD. In this connection, we use the term *scientifically based practices* to refer to instructional methods and other interventions and treatments that have been subject to scrutiny and scientific validation.

It is clear that identifying scientifically validated methods is extremely important and timely. Indeed, a cornerstone of the No Child Left Behind Act of 2001 is an emphasis on connecting educational practices to scientifically based research. It is noteworthy that the No Child Left Behind Act uses the phrase “scientifically based research” 111 times. Similarly, the Committee on Educational Interventions for Children With Autism, Division of Behavioral and Social Sciences and Education, National Research Council (2001) provides a list of characteristics that the committee contends are the effective educational intervention programs for children with ASD. The components include

early [age] entry into an intervention program; active engagement in intensive instructional programming for the equivalent of a full school day, including services that may be offered in different sites, for a minimum of five days a week with full-year programming; use of planned teaching opportunities, organized around relatively brief periods of time for the youngest children (e.g., 15–20 minute

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intervals); and sufficient amounts of adult attention in one-to-one or very small group instruction to meet individualized goals. (p. 6)

The committee also delineates the following elements and focus of effective educational interventions for children with ASD: “functional spontaneous communication, social instruction delivered throughout the day in various settings, cognitive development and play skills, and proactive approaches to behavior problems” (National Research Council, 2001, p. 6).

Related to the logic and increased emphasis on choosing effective practices, the present resource is designed to assist parents and professionals to critically evaluate and choose methods that have the highest probability of yielding benefit for children and youth diagnosed with ASD. We fully acknowledge that there are no universally effective methods. However, it is clear that certain methods have better track records than other approaches and that this information needs to be made available in a straightforward and simplified form.

The onset of ASD occurs early in life, and although the prognosis for persons with the disorder is generally considered to be poor, research continually supports improved prognoses for children who receive *early intervention*—that is, receiving services immediately after diagnosis. As noted earlier, there is no shortage of interventions and treatments from which to choose, some of which are associated with claims of a cure. Indeed, there is significant debate over which interventions and treatments for ASD hold the most promise. Even interventions that have been found to have an empirically sound foundation are not universally suitable and are frequently involved in controversies related to individualized use, outcome claims, exclusive and extensive use, and so forth. That the list of intervention options for children and youth with ASD is ever increasing is further exacerbating the problem of professionals’ and parents’ abilities to choose the most efficient and effective treatments and intervention methods. To help sort through the possible interventions, we discuss a variety of treatments for children and youth with ASD in this resource and include our analysis and opinion of the literature related to each method. We typically use a common format for each of our reviews: (1) age, ability, and developmental level appropriateness for the intervention; (2) a description of the intervention or treatment; (3) reported benefits and effects associated with the intervention or treatment; (4) a synthesis of how outcomes associated with use of the intervention or treatment relate to individuals with ASD; (5) a discussion of who is best qualified to effectively implement the intervention or treatment, and how, where, and when the treatment is best administered; (6) potential risks associated with the use of the intervention or treatment; (7) the price of utilizing the intervention or treatment;

(8) methods for evaluating the effectiveness of the intervention or treatment with individuals with ASD; (9) conclusions related to the options we reviewed, including our recommendation for use; and (10) references, resources, and related suggested readings.

For the purpose of organization, the interventions and treatments we reviewed are grouped within one of the following five broad categories: (1) interpersonal relationship interventions and treatments, (2) skill-based interventions and treatments, (3) cognitive interventions and treatments, (4) physiological/biological/neurological interventions and treatments, and (5) other interventions and treatments. We also group the interventions and treatments we review as (1) scientifically based, (2) a promising practice, (3) a practice for which there is limited supporting information, or (4) an intervention or treatment that is not recommended. We define *scientifically based practices* as those that have significant and convincing empirical efficacy and support. A *promising practice* refers to a method that appears to have efficacy and utility with individuals with ASD, even though the intervention requires additional scientific support to be considered a scientifically based method. A *practice for which there is limited supporting information* is used to describe interventions and treatments for which there is little or no scientific evidence. That is, these methods are available for use with individuals with ASD, although it is unclear if they have utility and efficacy. Thus, if an intervention or treatment is judged by us as lacking support, it is not an indication that it is necessarily without merit. Rather, this rating indicates that evidence is lacking to make an objective, scientific judgment. Finally, we use the descriptor *not recommended* to refer to interventions and treatments that have been shown to lack efficacy and that may have the potential to do harm.

See the following table for a list of the interventions and how we rated each one. A detailed explanation of each rating follows the table.

	<i>Chapter 1: Interpersonal Relationship Interventions and Treatments</i>	<i>Chapter 2: Skill-Based Interventions and Treatments</i>	<i>Chapter 3: Cognitive Interventions and Treatments</i>	<i>Chapter 4: Physiological/ Biological/ Neurological Interventions and Treatments</i>	<i>Chapter 5: Other Interventions, Treatments, and Related Agents</i>
Scientifically Based Practice		<ul style="list-style-type: none"> • Applied Behavior Analysis (ABA) • Discrete Trial Teaching (DTT) • Pivotal Response Training (PRT) 	<ul style="list-style-type: none"> • Learning Experiences: An Alternative Program for Preschoolers and Parents (LEAP) 		

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	<i>Chapter 1: Interpersonal Relationship Interventions and Treatments</i>	<i>Chapter 2: Skill-Based Interventions and Treatments</i>	<i>Chapter 3: Cognitive Interventions and Treatments</i>	<i>Chapter 4: Physiological/ Biological/ Neurological Interventions and Treatments</i>	<i>Chapter 5: Other Interventions, Treatments, and Related Agents</i>
Promising Practice	<ul style="list-style-type: none"> • Play-Oriented Strategies 	<ul style="list-style-type: none"> • Assistive Technology • Augmentative Alternative Communication (AAC) • Incidental Teaching • Joint Action Routines (JARS) • Picture Exchange Communication System (PECS) • Structured Teaching (TEACCH) 	<ul style="list-style-type: none"> • Cognitive Behavioral Modification • Cognitive Learning Strategies • Social Decision-Making Strategies • Social Stories 	<ul style="list-style-type: none"> • Pharmacology • Sensory Integration (SI) 	
Limited Supporting Information for Practice	<ul style="list-style-type: none"> • Gentle Teaching • Option Method (Son-Rise Program) Floor Time • Pet/Animal Therapy • Relationship Development Intervention (RDI) 	<ul style="list-style-type: none"> • Fast ForWord • van Dijk Curricular Approach 	<ul style="list-style-type: none"> • Cartooning • Cognitive Scripts • Power Cards 	<ul style="list-style-type: none"> • Auditory Integration Training (AIT) • Megavitamin Therapy • Scotopic Sensitivity Syndrome (SSS): Irlen Lenses 	<ul style="list-style-type: none"> • Art Therapy • Candida: Autism Connection • Feingold Diet, Herb, Mineral, and Other Supplements • Gluten-Casein Intolerance • Mercury: Vaccinations and Autism • Music Therapy
Not Recommended	<ul style="list-style-type: none"> • Holding Therapy 	<ul style="list-style-type: none"> • Facilitated Communication (FC) 			

Definitions of Categories:

Scientifically Based Practice: The interventions and treatments with this rating have undergone a substantial amount of rigorous research. The evidence repeatedly and consistently provides similar results that prove children and youth with ASD display a significant increase in skill acquisition as a consequence of the intervention.

Promising Practice: Interventions and treatments in this category have (1) been widely used for several years without any or with few adverse outcomes, and/or (2) undergone research that suggests that children and youth with ASD respond favorably and display skill acquisition as a consequence of the intervention. However, these practices require additional scientific evidence to be considered truly scientifically based.

Limited Supporting Information for Practice: Interventions and treatments in this group have been subjected to limited research with children and youth with ASD, are not widely being utilized with children and youth with ASD, or reflect a wide range of results (poor to favorable) when used with children and youth with ASD.

Not Recommended: Interventions and treatments that fall in this category are those that have (1) undergone a substantial amount of rigorous research and the evidence proves that the intervention or treatment does not increase skill acquisition or favorable results with children and youth with ASD, and/or (2) there have been serious detrimental effects and outcomes for some children and youth with ASD as a result of the use of the intervention or treatment.

We fully acknowledge that we have not included every possible option available for use with individuals with ASD. Moreover, we recognize that our reviews and conclusions are based on our interpretations of the literature and our professional opinions. Nevertheless, we are hopeful that this resource will assist parents and professionals to select and to implement maximally effective methods for individuals with ASD. Finally, this book reflects our perception and perspective that there is not a single method that should be exclusively used to meet the varied needs of individuals with ASD and their families. Indeed, in our opinion, the most effective programs are those that incorporate a variety of best practice methods. It is our hope that we have been able to offer a useful resource for facilitating effective intervention and treatment choice decision making for those directly connected to individuals with ASD.

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