Autism Spectrum Disorders

From Theory to Practice

Third Edition

Pearson

Laura J. Hall

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From Theory to Practice

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LAURA J. HALL
San Diego State University

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330 Hudson Street, NY, NY 10013

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About the Author

Laura J. Hall, Ph.D., is a professor and chair of the Department of Special Education at San Diego State University (SDSU). She has been working with individuals with autism spectrum disorders and their families for more than 35 years and is responsible for the creation of the master's degree program with a specialization in autism at SDSU. Her current research interests focus on factors that facilitate the implementation and sustained use of evidence-based practices by educators and paraprofessionals working with learners with autism spectrum disorders. Dr. Hall's involvement with several boards of nonprofit organizations supporting autism is another way in which she is working to develop a solid community of practice in San Diego.

Dedicated to

Pat Krantz, Lynn McClannahan, and Sam Odom

Inspirational role models and mentors

Preface

While researchers are trying to determine the currently unknown cause of autism spectrum disorders (ASD), there is a need for effective strategies to address the characteristics displayed by individuals with this classification. The need for knowledgeable and skilled educators who can identify, implement, and sustain the use of evidence-based practices is critical and is likely to remain so well into the future. *Autism Spectrum Disorders: From Theory to Practice* is a comprehensive text that provides information about ASD from up-to-date research on brain development and genetics to working with families to prepare adolescents and young adults for transition. Descriptions of common practices used by educators are organized by theoretical perspective. How to determine whether there is research support for a practice, or whether a practice is evidence-based, is explained. The research support, or lack thereof, is provided following each description of the approach, programs, and current practices.

New to This Edition

The passing of the Combating Autism Act in 2006 and the increase in prevalence of ASD that continues to be reported by the Centers for Disease Control and Prevention have resulted in increased funding for research and increased attention by researchers. Each chapter in this revised edition has been updated to reflect the most current research outcomes. This edition also uses the results from several publications of literature reviews in 2015 that have identified evidence-based strategies and comprehensive programs (e.g., from the National Standards Project and the National Professional Development Center on Autism Spectrum Disorders) as the basis for reviewing common practices. The criteria used for describing autism spectrum disorder are taken from the revised diagnostic manual from the American Psychiatric Association (DSM-5) and relate current research and practice to these criteria. The following is a list of changes and updates in the third edition of *Autism Spectrum Disorders*:

- Literature reviews of all content areas have been updated, and description and emphasis on the identification of practices and strategies with sufficient research evidence, as determined by the National Standards Project and the National Professional Development Center on ASD, will provide state-of-the-art information about which practices are scientifically based.
- New to this edition is the highlighting of *Sensory Considerations* found in each chapter. Examples of practices that have been used to address the possible sensory issues such as hyper- or hyposensitivity to sensory stimuli and the associated challenges for individuals on the spectrum can be found throughout the text.

- A chapter on systems of support for individuals with ASD and their families (Chapter 10) has been added. Content on the influence of culture and how to work with families from diverse backgrounds is a main focus of this chapter. The importance of collaboration within and across systems, such as between families and school personnel and between school personnel and agencies, is emphasized. The importance of advocating for policy and a history of examples of parent-initiated efforts resulting in policy changes are included.
- Cultural and linguistic considerations are emphasized throughout the text, and especially so in Chapter 10, so that all practitioners are sensitive, knowledgeable, and aware of the influences of culture and language and can implement culturally responsive strategies.
- Each chapter contains suggestions for future research, and these updates take into account research questions that have been addressed in recent years and new questions that have arisen as a result of ongoing research. Students planning to conduct research will find the summaries of current research and recommendations for future research helpful in designing projects.

Organization of the Book

The text is organized into three parts. Part I includes three introductory chapters. Chapter 1 focuses on the current approaches to determining the causes of autism spectrum disorders and provides a description of strategies used to address this disorder on a physiological level, such as through prescription medication, diet, or activities to arouse or calm the sensory systems. Chapter 2 provides information regarding assessment that is organized by purpose (screening, diagnosis, educational planning). The emphasis in this chapter is on curriculum-based assessment that links assessment results to educational practice. The identification and effective implementation of evidence-based strategies are addressed in Chapter 3. A description of the individualized education program (IEP) process is provided. The importance of working in collaboration with families is emphasized with recommendations for effective practice.

The following three chapters describe the programs and practices used to increase the skills of individuals with autism spectrum disorders and comprise Part II of the book. Each chapter is organized by theoretical perspective. Chapters 4 and 5 focus on principles, programs, and strategies based on applied behavior analysis. Programs and practices influenced by the developmental, social-relational, transactional, and cultural theories are included in Chapter 6. An emphasis on working collaboratively with families is discussed in all approaches, regardless of theoretical perspective. Each approach or program model includes a brief description of the theoretical perspective, a historical overview of strategies used by educators working with individuals with autism spectrum disorders, definitions and descriptions of key concepts of the approach, examples and illustrations of strategies based on key concepts, a description of a model program or classroom based on the approach, and a summary of the research evidence for the approach and practices.

Part III contains four chapters. The first two put together the information across the theoretical approaches described in Part II to address two areas that are frequently a focus for educators: communication (Chapter 7) and social relationships (Chapter 8). Chapter 9 focuses on preparing adolescents and young adults for transition. Best practices are summarized with examples of high-quality programs. Chapter 10 focuses on the systems of support necessary to achieve optimal outcomes for individuals with ASD and their families. Strategies for working in collaboration with diverse families, colleagues in schools and agencies, paraprofessionals, and administrators are emphasized. This last chapter (and the book) concludes with a description of the major contributions to the field made by families and the importance of working in collaboration with families to influence policy, change systems, and build communities of practice.

Features of the Text

In Their Words

Boxes called In Their Words, found in each chapter, feature input and quotes from professionals and parents of individuals with autism spectrum disorders and interviews with adults identified on the spectrum. These features augment the chapter content by enabling the reader to obtain the perspective of professionals using various theoretical approaches (e.g., Drs. Krantz and McClannahan, Dr. Mesibov, Dr. Wolfberg) from various disciplines such as speech-language pathology (Colleen Sparkman), occupational therapy (Janinne Karahalios), psychology (Dr. Natacha Akshoomoff, Dr. Brooke Ingersoll), and special education (Dr. Dean Fixsen, Dr. Bonnie Kraemer, Dr. Eleanor Lynch, Dr. Angela McIntosh, Sheila Wagner). Special education teachers (Cindy Bolduc, Penelope Bonggat), parents (Laura Wood, Juan and Sharon Leon), and adults with autism spectrum disorders (Erik Weber) provide their perspective on effective practices, diagnosis, and suggestions for preparing for postsecondary education.

Sensory Considerations

Boxes called Sensory Considerations, found in each chapter, highlight assessments and interventions used to address the sensory issues experienced by individuals with ASD, such as hyper- or hyposensitivity to stimuli, one of the diagnostic criteria added to the DSM-5.

Evolution of Practices

The evolution of practices in special education is included in most chapters to reflect the development of approaches and practices over time and to capture the historical progression of events or strategy development. Educational practices with learners with autism spectrum disorders are far from static. These practices are influenced by changes in philosophy, policies, and research outcomes.

Research Emphasis

The importance of research is emphasized throughout the text, including a review of the evidence for practices and suggestions for future research. This emphasis will be particularly helpful to master's degree and doctoral candidates, but it will provide direction for all practitioners who are working to further the field with information on the effectiveness of intervention strategies. Understanding the research evidence, or lack thereof, is important for all educators who are required to use only scientifically based practices.

Learning Outcomes, Suggestions for Discussion, Resources

Each chapter begins with a list of learning outcomes for the information gained by reading the chapter content. Chapters conclude with two features. The first is a list of suggestions for discussion that are focused on key points from the respective chapter. These suggestions for discussion include a suggestion for a debate (usually number 3 in the list) on a particular issue from the chapter. A list of resources (books and websites) provides additional information on various topics found in the respective chapter.

Acknowledgments

This book would not have been possible without the education, professional guidance, and encouragement provided by my professional mentors Pat Krantz, Lynn McClannahan, Beth

Sulzer-Azaroff, Gail McGee, and Sam Odom. I am also grateful to the individuals with autism spectrum disorders who taught me a great deal about how to address educational challenges with clarity, consistency, and humor. I am appreciative of the parents of the learners with ASD who have sought and supported my skills and have served as excellent partners. A special thank-you goes to my students, who have been exceptional research collaborators and who inspire me with the energy, enthusiasm, and affection that they bring to their work with learners and their families. I continue to learn from each of them.

This book would not have been possible without those at Pearson, such as Ann Castel Davis, who worked with me to actualize our vision for the text and who clearly identified the book's strengths and areas that could be made stronger for the third edition; and Carolyn Schweitzer, who provided immediate feedback on the media content for all initial chapter submissions. I sincerely appreciate the outstanding editing from Katrina Ostler and her staff who clearly read every line of the book. I would also like to thank the reviewers, who provided excellent suggestions that contributed to the improvements in this third edition: Joanna Bobzien, Old Dominion University; Marissa Congdon, Cal State Bernadino; and Maria Moya, College of Southern Nevada.

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CHAPTER ONE

Classification and the Physiological Approach

LEARNING OUTCOMES

At the conclusion of this chapter, the reader should be able to:

- State the criteria for the diagnosis of autism spectrum disorder (ASD) according to the classification system developed by the American Psychiatric Association, the DSM-5.
- Explain the possible causes of autism spectrum disorders currently under investigation by researchers.
- Discuss physiological interventions for individuals with ASD, provide a rationale for the use of sensory activities, and consider the implications for the lack of evidence to support sensory-based treatments.
- Describe the ways in which an occupational therapist can be a helpful collaborator for addressing the sensory needs of individuals with ASD.

The Autism Society of America (ASA) uses a ribbon of puzzle pieces as the symbol of autism spectrum disorders. This symbol is used because so much about autism spectrum disorders (ASD) remains unknown, or a puzzle.

Written on the About Autism page of the ASA website is the comment: ASD is defined by a certain set of behaviors and is a "spectrum condition" that affects individuals differently and to varying degrees. There is no known single cause of autism, but increased awareness and early diagnosis/intervention and access to appropriate services/supports lead to significantly improved outcomes (Autism Society of America, 2016).

In this chapter the currently used classification systems of the *Diagnostic and Statistical Manual of Mental Disorders* and the *International Classification of Diseases* and the classifications under the Individuals with Disabilities Education Act will be described. Each of these systems represents the consensus opinions of the authors at the time of publication, and all are revised as additional information about autism spectrum disorders is learned.

The evidence for a genetic influence on autism spectrum disorders and the current areas of focus in determining the cause will be explored. Much of the effort to find the cause focuses on the biology and physiology of individuals with ASD and their families. Interventions that address the biological or physiological aspects of an individual with autism spectrum disorder, such as the prescription of medication, recommendation for a special diet, and organizing activities that address arousal (calming or stimulating) such as exercise and sensory interventions, will be reviewed. In summary, this chapter includes a description of various classification systems for autism spectrum disorders; an explanation of the genetic, biological, and physiological areas under investigation to determine a cause; and descriptions of interventions aimed at changing the physiology of the individual.

Classification Systems of Autism Spectrum Disorders and Prevalence

Classification of the characteristics associated with autism spectrum disorder (ASD) into a specific category occurred in the 1940s by Leo Kanner, a U.S. psychiatrist (1943), and Hans Asperger, a German pediatrician (1944). Influenced by adult psychiatry, the term **autistic** (derived from the Greek word *autos* for "self") was used as the description of negative symptoms when someone was entirely uninterested in the outside world (Houston & Frith, 2000). Kanner described a triad of impairments (social difficulties, communication problems, and repetitive and restricted activities) in his paper about 11 children from the Child Psychiatric Unit at Johns Hopkins University where he worked (Mesibov, Shea, & Adams, 2001).

Lorna Wing was one of the first people to use the term **spectrum** when describing a group of individuals displaying the characteristics of autism. In their project conducted in the 1970s (the Camberwell study), Wing and Gould (1978) found that individuals with autism varied in the degree of severity of their displayed characteristics as well as in the form of differences and delays, leading the authors to begin to discuss this spectrum of disorders (Houston & Frith, 2000). Included in this spectrum were individuals with no cognitive delays, referred to by the researchers as individuals with high-functioning autism, and individuals with Asperger syndrome (Wing, Leekam, Libby, Gould, & Larcombe, 2002). Wing was aware of Hans Asperger's work, and when she began to publish her research in the early 1980s, she used the term **Asperger syndrome**, resulting in international awareness of this classification. Prior to this time, Asperger's work was not well known due to the fact that it was published only in German (Mesibov et al., 2001).

Diagnostic and Statistical Manual of Mental Disorders

One of the main classification systems used internationally is the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) published by the American Psychiatric Association (APA). Details of the characteristics that classify individuals with varying diagnoses are made by a group of psychiatrists, psychologists, and physicians with expertise in the area. The criteria for the fifth edition of the manual were published in 2013. The focus of the revised DSM version is on the variability in severity of characteristics that comprise one category of autism spectrum disorder compared with the five distinct disorders of the pervasive developmental disorders in the DSM-III and IV (American Psychiatric Association, 1980, 1987, 1994, 2000) such as autistic disorder, Asperger syndrome, Rett's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS) (Volkmar, Reichow, Westphal, & Mandell, 2014).

There are two domains with criteria used for autism spectrum disorder reduced from three in the previous version (Volkmar et al., 2014) that include (a) persistent deficits in social communication and social interaction across contexts and (b) restricted, repetitive patterns of behavior, interests, and activities. In addition, (c) symptoms must be present in childhood that (d) limit and impair everyday functioning. Individuals must have deficits in all three subcategories of social communication and social interaction (deficits in [1] social-emotional reciprocity, [2] nonverbal communicative behaviors, [3] developing and maintaining relationships) and two of four subcategories of restricted and repetitive patterns of behavior ([1] stereotyped or repetitive speech, motor movements, or object use; [2] excessive adherence to routines or ritualized patterns of verbal or nonverbal behavior; [3] highly restricted, fixated interests; [4] hyper- or hyporeactivity to sensory stimuli) to receive a diagnosis (American Psychiatric Association, 2013). Children with this diagnosis may have skill areas where they are functioning similarly to typical peers or may even exceed the skills of peers in areas such as music, math, or reading.

The criteria for the DSM-5 represent a change in the classification category as well as the sub criteria that comprise the symptoms compared with earlier versions of the manual (American Psychiatric Association, 1980, 1987, 1994, 2000). Table 1.1 shows some of the changes in language and age of onset for the versions between 1980 and 2011. It appears from the changes in diagnostic criteria over

TABLE 1.1 Sample changes in diagnostic criteria for autism from the DSM

DSM III-1980	DSM IIIR-1987	DSM IV-1994 and TR-2000	DSM-5 2013
Onset before 30 months	Onset before 36 months	Delays or abnormal functioning in one area (social interaction, language or play) before 36 months	Symptoms in early childhood
Gross deficits in language development	Qualitative impairment in both verbal and nonverbal communication	Qualitative impairment in communication	No separate impairments for communication
Pervasive lack of responsiveness to others	Qualitative impairment in reciprocal social interaction	Qualitative impairment in social interaction	Deficits in social-emotional reciprocity and social relationships

time that children can get a diagnosis if fewer characteristics appear later. Hyper- or hyposensitivity to sensory stimuli was included in early diagnostic versions (DSM III, 1980) and again in the latest version (American Psychiatric Association, 2013).

The DSM-5 criteria were created under the assumption that deficits in communication and social interaction are inseparable and it is more accurate to consider them together and influenced by contextual and environmental variables. This decision was made based on literature reviews, expert consultation, and workgroup discussions (American Psychiatric Association, 2013). Because distinctions among the disorders in previous versions of the manual were found to be inconsistent over time and the use of diagnostic categories varied across sites, the use of a single diagnostic category (autism spectrum disorder) was adopted in the latest version. In the DSM-5, it is recommended that the level of severity for social communication and restricted interests and repetitive behaviors is considered on a scale of 1 (requiring support) to 3 (requiring very substantial support).

International Classification of Diseases

The *International Classification of Diseases*, published by the World Health Organization (WHO), is in its tenth version and is referred to as the ICD-10. The ICD-11 revision will be an online tool that has a target completion date of 2017. This classification system is used widely in Europe as well as in other countries worldwide. Autism first appeared in the ICD in 1967, when it was listed as *infantile autism* under one of the subtypes of schizophrenia. In 1974, infantile autism was classified under behavior disorders of childhood but without defining diagnostic criteria (Leekam, Libby, Wing, Gould, & Taylor, 2002). The ICD-11 will use the term *autism spectrum disorder* (7A20) under the category of mental and behavioral disorders with the subclassifications of with a disorder of intellectual development or without, with or without functional language, and with or without loss of previously acquired skills and all combinations of these factors. It is defined as a neurodevelopmental disorder as such:

> Autism spectrum disorder is characterized by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour and interests. The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities. Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings, although they may vary according to social, educational, or other context (World Health Organization, 2016).

Individuals with Disabilities Education Act (IDEA)

Autism was added as a separate category of disability that may require special education services in 1990 under PL 101–476, the Individuals with Disabilities Education Act (Knoblauch & Sorenson, 1998). To receive special education, the child (1) must have one or more of the disabilities from a list that includes autism and (2) must require special education and related services. Autism is defined by IDEA as 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, stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. Individual states have their own criteria for eligibility of early intervention and special education services. Educators should be aware of what their own state requires for eligibility.

Classification systems are important in order to determine the outcomes of research. Replication is a hallmark of good science. If an intervention is demonstrated as helpful for a group of individuals classified with ASD, it will be important to replicate the intervention with a similar group prior to claiming effectiveness. Without a classification system and the inherent definitions of characteristics, this replication would not be possible. Classification or diagnosis is also important for parents who are eager to understand the atypical behavior of their child.

Prevalence

The **prevalence** is the number of cases of a condition that exists at a particular time in a defined population. The estimated prevalence rates following the creation of the classification category for autism in the 1940s was considered to be 4 or 5 in 10,000 for decades (Stevens et al., 2007). This estimate increased in the mid-1990s to 10 per 10,000 (1 in 1,000) for autism and 22 per 10,000 for pervasive developmental disorder (PDD) (Mauk, Reber, & Batshaw, 1997). A review of 54 studies of prevalence completed internationally published between 1966 and early 2013 for 23 countries revealed a correlation between prevalence rate and publication year with higher rates in more recent years (Hill, Zuckerman, & Fombonne, 2014). The mean international prevalence rate from recent surveys is 66/10,000 or 1 in 152. Research findings indicate that low SES, minority, and immigrant populations experience problems of underdiagnosis (Hill et al., 2014). It is important to note that the increase in prevalence rates could be attributed to increased awareness and access to services and that "the possibility that a true change in the underlying incidence has contributed to higher prevalence figures remains to be adequately tested" (Hill et al., 2014, p. 90).

Research indicates that regression, or loss of skills such as use of language, occurs in 1 in 4 children diagnosed with ASD and is associated with more severe symptoms (Fombonne, Quirke, & Hagen, 2011). If regression occurs, it is likely to happen during the 6 months prior to age 2. Researchers have found that there is no difference on a range of outcome measures for children with or without regression (Ozonoff, Heung, & Thompson, 2011). The median percentage of individuals with autism spectrum disorders that have a co-occurring intellectual disability is 65% as calculated from 14 studies completed since 2000 (Dykens & Lense, 2011). It should be noted that estimates of how often intellectual disabilities occur with ASD vary widely and are influenced by definition and classification systems. Compared with the general population, epilepsy is 10 to 30 times more prevalent in individuals with ASD and occurs most often when there is a moderate to severe intellectual disability (Tuchman, 2011).

The Autism and Developmental Disabilities Monitoring (ADDM) Network funded by the Centers for Disease Control and Prevention estimates the prevalence of autism spectrum disorders in the United States, or the number of cases identified, to be 1 in 68 (Christensen et al., 2016).

This information is based on data obtained across 11 states in the United States during 2012. Researchers in each of the states collected data from health and school records to determine the number of 8-year-olds diagnosed with ASD as well as the ethnic background of these students. The authors comment that the 11 states included in the study (Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, South Carolina, Utah, and Wisconsin) are not representative of the nation and that the prevalence rates should be used with caution (Stevens et al., 2007). The prevalence rates vary among states, with an earlier study reporting lowest rates for South Carolina (1 in 81) and highest for New Jersey (1 in 41) (Christensen et al., 2016). The ratio of 1 in 68 remains the same as the prevalence reported from the 2010 data. Although the prevalence stayed the same for most of the states, there were increases in New Jersey and Wisconsin. The authors of the ADDM report state that it is too soon to say if the prevalence rate for ASD is stabilizing (Christensen et al., 2016). This high prevalence rate of less than 1 in 1,000 means that ASD is now considered a common disease (Bailey, 2016).

Consistently more boys than girls are classified with autism spectrum disorders, with a ratio of approximately 4 or 5 boys to 1 girl. White non-Hispanic children were 1.2 times more likely to be identified with ASD than Black non-Hispanic children and 1.5 more likely than Hispanic children (Christensen et al., 2016). Black and Hispanic children were also less likely to be evaluated for concerns by age 3 compared with White children, among whom 43% are evaluated for concerns prior to age 3. Approximately one-third (32%) also had an intellectual disability, 22% were considered borderline, and the remaining 44% had average to above average intellectual ability.

The majority of children do not receive a diagnosis by a community provider until age 4. In a prevalence study conducted by the ADDM in five of the participating states focusing on 4-year-olds, the authors found that those states that had both health and education records for review had twice as many children with ASD identified than those that relied on health records alone (Christensen et al., 2015). The authors conclude that the special education system has an important role in identifying children with ASD. Across the five states the prevalence rate for 4-year-olds was lower than for 8-year-olds, indicating increased identification over time (Christensen et al., 2015).

Whether the increase in prevalence rates represents a true increase in incidence of ASD has yet to be determined (Fombonne et al., 2011). The factors that may have contributed to the increase in prevalence include (1) an increased awareness by the public and by physicians and psychologists who make the diagnosis, (2) the broadening of the classification to include pervasive developmental disorder that requires minimum criteria for classification, (3) different methods for case finding, and (4) service availability (Fombonne et al., 2011). Epidemiologists also argue that ASD is a cultural phenomenon and that how it is conceptualized influences both diagnosis and treatment; they explain ASD as an interplay of biological, cultural, and psychological phenomena (Grinker et al., 2011).

What Causes Autism Spectrum Disorders?

History of Attribution of Cause

Autism has long been considered a classification of a mental disorder. Early individuals with moderate to severe delays in language and social skills would have been placed in institutions to be "treated" by the medical establishment of the time. Kanner, a psychiatrist, first wrote about what was once called infantile autism and the associated symptoms in his paper in 1943. It is likely that individuals with autism who were high functioning were considered odd loners who were not classified as needing intervention.

In the 1950s, psychiatrist Bruno Bettelheim attributed the symptoms of autism to uncaring and detached mothers who did not love their

1.1

IN THEIR WORDS

Laura Wood

Three Children on the Spectrum

My husband and I have three wonderful sons. They are all on the autism spectrum. Our oldest son Alex's diagnosis at age 2.5 came as a tremendous blow to us, as it does to every family grappling with this disorder. At that time our twins were 5 months old and we were thoroughly overwhelmed by our responsibilities. But we managed to launch a high-quality home intervention program for Alex and felt that we were doing everything we could do for him.

As the shock of Alex's diagnosis wore off a bit, I did start overanalyzing certain observations of the twins' behavior. Were they smiling? Paying attention to faces? During their first year of development, despite my hypervigilance, I believed it to be unlikely that they were autistic. I had not yet heard about the increased likelihood of autism in siblings of autistic children, so I told myself I was being unnecessarily paranoid.

But as the months went by and certain developmental milestones were missed or seemed ambiguous, the nagging feeling returned and slowly I realized that the nightmare scenario was coming to pass. The twins were both diagnosed with autism spectrum disorder shortly before their second birthday.

The most obvious impact of having kids "on the spectrum" is the financial commitment required for their home therapy. We are extremely lucky in Seattle to have a wonderful integrated preschool that all three kids attend for specialized instruction, but supplemental home programs are also recommended for two of our children, and the staggering cost of those programs is not covered by health insurance.

In addition, as many parents of children with special needs will tell you, guilt is ever-present. Sometimes the guilt has a specific source (Am I spending enough time encouraging communication and appropriate play? Have we set up *enough* hours of home therapy?). Other times the guilt is vague, intangible, and inexplicable.

I have times when I feel bitter and isolated. I look at other families with typically developing children with longing or even with anger. They can't know what it's like to take their children to countless therapy appointments and spend tens of thousands of dollars on essential therapy. How can I relate to these parents who take for granted their child's imaginative play skills or brag recklessly about their baby's first words? And how can they relate to me when I occasionally confess the reason why my kids don't always respond appropriately to a peer's invitation to play? Unless autism has touched their lives in some way, a blank look tinged with pity is all those parents can muster.

But in other ways I recognize the gifts sent our way by this unexpected path in life. There are several wonderful teachers and therapists who would never have been in our lives had it not been for the autism in our family. And my children have reminded me that there are different varieties of intelligence beyond what we think of as typical.

My kids are sweet, wonderful rays of sunshine in my life. They give me so much joy that all the worry and guilt and expense are absolutely worthwhile. I have already learned from them, and I'm sure they have more to teach me as we continue through our lives together.

children enough. Treatment consisted of removing the children from these so-called **refrigerator mothers**; offering psychoanalysis or counseling to the mother; and providing play therapy to the child, ideally in Bettleheim's institute in Chicago. The disorder was thought to occur in middle-class Caucasian families where both parents were educated. During this period of history, not only did the mothers of children with autism have to care for a child with challenging and unusual behaviors, they also experienced the added burden of being blamed as the cause.

In 1964, Bernard Rimland published the book *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*, which attributed the cause of autism to biology rather than poor parenting. Rimland dedicated his career to addressing the biological issues that contribute to and result from autism spectrum disorders. He had long hypothesized that there are brain differences in individuals with ASD compared to the brains of typically developing children. Rimland founded the Autism Research Institute (ARI) that supports the project Defeat Autism Now (DAN). Annual conferences are held where physicians present information on possible metabolic (interrelated chemical interactions that provide the energy and nutrients) contributions to symptoms and suggest diets that can be used to avoid the side effects of toxins for individuals with ASD.

Genetic Influences

> Autism is a behaviorally defined lifelong neurodevelopmental disorder, with strong evidence for a complex genetic predisposition. (Lamb, 2011, p. 669)

Autism is currently considered a **neurological disorder** that is influenced by both environmental (including the in-utero environment) and genetic factors (Sigman, Spence, & Wang, 2006). Initial evidence for a genetic contribution to ASD is found in a series of twin studies conducted across several countries (e.g., United Kingdom, Scandinavia, United States) with similar outcomes (Bailey et al., 1995; Ritvo, Freeman, Mason-Brothers, Mo, & Ritvo, 1985; Rutter, 2005; Steffenburg et al., 1989). When one twin in a monozygotic pair of twins (identical) was diagnosed with autism, there was a high likelihood that the second twin, with the same DNA, also was diagnosed with autism (Cook, 1998). However, in dizygotic twins (fraternal), the concordance for the diagnosis for autism was very low. In addition to the twin studies, it has been found that the risk of autism for siblings of those identified on the spectrum is 15% to 20%, considerably higher than the population risk (.05% to .1%) (Lamb, 2011).

Results of surveys have revealed that relatives have an increased frequency of lesser variants of autism, including social, language, and repetitive behaviors (Dworzynski, Happe, Bolton, & Ronald, 2009; Rutter, 2005). This variation of the spectrum is referred to as the broad autism phenotype (BAP) (Ingersoll & Wainer, 2014; Sasson, Lam, Parlier, Daniels, & Piven, 2013) that describes individuals that have personality profiles related to the expression of subclinical characteristics of autism (Volkmar et al., 2014). The rate of BAP in first-degree relatives is estimated to be 57% (Ingersoll & Wainer, 2014). In adults, difficulties with social functioning result in less desire for close relationships and lower quality friendships (Ingersoll & Wainer, 2014).

The findings of a study investigating the broad autism phenotype among 711 parents of children with autism and 981 comparison parents using the Broad Autism Phenotype Questionnaire (Hurley et al., 2007) concluded that the parents of children with autism were more likely to have one parent with BAP characteristics than two parents with BAP and that the severity of autism was associated with having a parent with BAP characteristics compared with parental pairs with neither parent with the broad autism phenotype (Sasson et al., 2013). Although molecular genetic research has revealed loci in inherited, familial forms of ASD, there is substantial between-family locus heterogeneity (Piven et al., 2013), and molecular genetic studies have not identified the inherited factors of autism (Bailey, 2016). "Efforts to uncover that risk genotypes associated with the familial nature of autism spectrum disorder (ASD) have had limited success" (Piven et al., 2013, p. 1).

The current thinking is that "autism spans the genome" (Coleman & Betancur, 2005, p. 17), or is likely to be caused by multiple genetic loci on several chromosomes. Our genes are found on 23 pairs of chromosomes numbered from 1 to 22 and an X or Y chromosome. The larger the number of the chromosome, the smaller the size of that chromosome. When using specialized equipment, each chromosome appears in an X shape with the top arms, or p part, shorter than the lower and longer q portion.

New technology provides additional information about gene insertions, deletions, and the interactions related to autism; however, there remain approximately 100 genes that potentially create a risk for ASD, and these genes are involved in a wide range of biological mechanisms (Bailey, 2016). Some of the genes on the following chromosomes are hypothesized to contribute to ASD: chromosome 1p21.3 and 1q25.1-1q25.2, chromosome 3p14 and 3q26.31 (Kaymakcalan & State, 2011), chromosome 7q31.2 (Lamb, 2011), chromosome 13q21.32 (Kaymakcalan & State, 2011; Rutter, 2005), chromosome 15q11-q13 (Delahanty et al., 2011) (or the same region that is missing in Prader-Willi and Angelmann syndrome), chromosome 16p13.2 (Kaymakcalan & State, 2011), chromosome 19p and 19q (Rutter, 2005), chromosome 22q13.3 (Kaymakcalan & State, 2011), and the X chromosome (Coleman & Betancur, 2005; Rutter, 2005). Chromosome X is of particular interest due to the higher ratio of males to females with the disorder and because of fragile X syndrome (Hagerman, Narcisa, & Hagerman, 2011), which results in similar symptoms (Morrow & Walsh, 2011).

Although research has revealed possible links between genes and ASD, there has not been a set of genes that indicate a high risk for a large number of individuals, the heritability is not understood, and the sex difference remains unexplained. No firm conclusions can be drawn yet about the influence of genes on biological pathways (Rutter & Thapar, 2014). It may be that, similar to intellectual disability, there is no one unified neurobiology for ASD but multiple paths that result in similar biological and behavioral characteristics (Bailey, 2016). However, researchers are continuing to explore the influence of gene networks that may result in ASD. One promising line of research is analyzing blood samples to determine if biomarkers for ASD can be found (Pramparo et al., 2015). One study using blood samples from boys ages 1 through 4 with ASD and a control group identified differentially coexpressed genes in translation and immune/inflammation functions for the boys with ASD in 83% of the sample. The authors conclude that these results mean that a blood-based clinical test for at-risk male infants and toddlers could be created and routinely implemented in pediatric settings (Pramparo et al., 2015). Replication of these findings for the identified biomarkers is needed.

Differences in Structure and Function of the Brain

In Kanner's original description of autism, he noted that 5 of the 11 children had large heads (Minshew et al., 2005). At birth the head circumference of infants who later were diagnosed with autism is near normal; however, by 6 to 14 months of age (Hazlett et al., 2012), the head circumference becomes enlarged, reflecting early brain and cerebrum overgrowth (Courchesne, Webb, & Schumann, 2011; Hazlett et al., 2011) that continues during the first 2 years of life (Courchesne, 2011). In a study of 270 infants at high risk for ASD and 108 low-risk controls during the first 2 years of life, findings indicated a significant increase in the corpus callosum area and in thickness for children with ASD starting at 6 months of age compared with the control group and that these difference diminish by age 2 (Wolff et al., 2015). See Figure 1–1 for a model of a typical brain.

The brain overgrowth and dysfunction is probably due to a dysregulation of layer formation and layer specific neuronal differentiation that occurs during prenatal development (Stoner et al., 2014). The most likely cause is

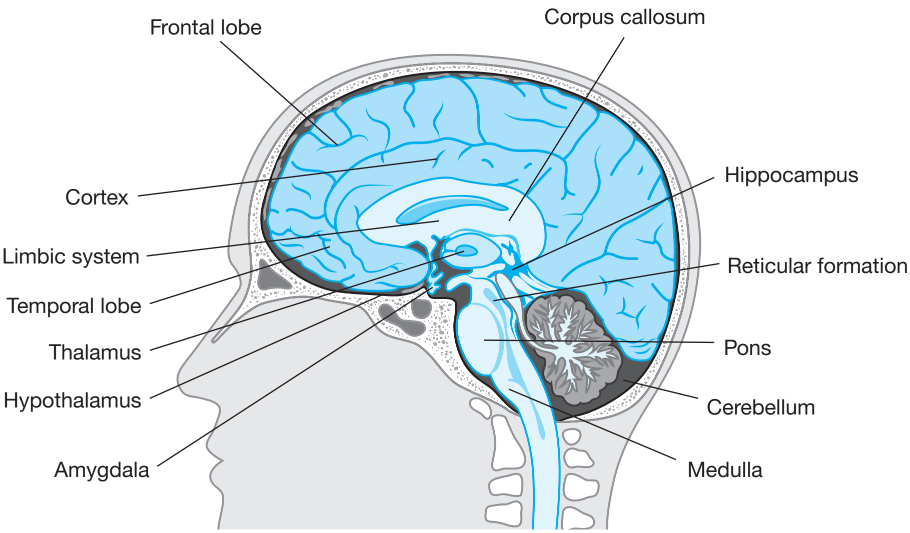


FIGURE 1–1 Key parts of the brain: The figure shows a vertical slice near the middle of the brain

excess neuron numbers due to dysregulation of neurogenesis, or the lack of the normal pruning and connecting of neurons. Researchers using an analysis of postmortem data in toddlers with ASD hypothesize that there could be axonal overconnectivity in the frontal brain lobes and amygdala (Solso et al., 2016).

Temple Grandin, professor of animal science at Colorado State University who is one of the most well-known adults with autism, writes the following in her book titled *The Autistic Brain* (Grandin & Panek, 2013, p. 27–29).

> Autistic brains aren't broken. My own brain isn't broken . . . They just didn't grow properly. . . . Autism researchers have contacted me over the years to ask permission to put me in this scanner or that. I'm happy to oblige . . . Thanks to a scan at UCSD School of Medicine's Autism Center of Excellence, I know my cerebellum is 20 percent smaller than the norm. . . . so this abnormality probably explains why my sense of balance is lousy. In 2006, I participated in a study at the Brain Imaging Research Center in Pittsburgh and underwent imaging with a functional MRI scanner and a version of MRI technology called diffusion tensor imaging (DTI). While fMRI records regions in the brain that light up, DTI measures the movement of water molecules through white matter tracts—the interoffice communication among the regions. The fMRI . . . showed a lot less activation in response to faces than (a control) did. The DTI imaging indicated that I am over-connected . . . way more connections than usual."

Autism does not result from a problem with one location in the brain but from abnormalities within one or multiple neural systems and with under-connectivity of cortical systems (Minshew, Scherf, Behrmann, & Humphreys, 2011; Coleman, 2005). Magnetic resonance imaging (MRI) studies have revealed the overgrowth in the frontal and temporal lopes of the brain and the amygdala (Courchesne et al., 2011). The frontal lobes are considered to play a role in memory formation and emotional expression, and patients with frontal lobe damage demonstrate a decreased ability to respond to stimuli in the environment (Reichler & Lee, 1989). The frontal lobes are the part of the brain where planning, organizing, self-monitoring, inhibition, flexibility, and working memory, or the cognitive construct of executive functioning, are considered to occur (Ozonoff, South, & Provencal, 2005). The amygdala is responsive to stimuli that are highly rewarding, such as a mother's face, for typical infants (Courchesne et al., 2011).

Neuroimaging studies that access areas of the brain reacting during different tasks or functional MRIs have revealed that regions associated with object perception are more active during tests requiring the identification of embedded figures given to subjects with ASD compared with prefrontal regions more active in typical subjects (Ring, 1999). There is also a reported inability to shift attention accurately and rapidly between sensory modalities measured in reaction times to the random presentation of visual and auditory stimuli (Courchesne et al., 1994). Neuroimaging studies also provide evidence for abnormalities in the systems that underlie face and voice processing (Sigman et al., 2006). There is a pattern in high-functioning individuals with ASD having preservation or enhancement of simple feature processing of visual information with affected information processing that requires integration (Minshew et al., 2011). Hypoactivation has also been found in the amygdala during certain tasks that may reflect less interest or reduced emotional arousal during those tasks (Schultz & Robins, 2005).

Elison, Wolff, and colleagues (2013) conducted a study with infants and found that measurable differences in a white matter fiber bundle connecting the amygdala to the prefrontal cortex and anterior temporal pole measured at six months predicted individual differences in responding to joint attention at 9 months of age. Another study examined the visual orienting latencies of 7-month-olds at risk for autism and found an atypical pattern in the posterior cortical circuits for high-risk infants compared with low-risk infants (Elison et al., 2013). A study that used functional magnetic resonance imaging (FMRI) during a presentation of a bedtime story read to 40 typical 3- and 4-year-olds and 40 with ASD found that toddlers at risk for ASD displayed a deficient left hemisphere response to speech sounds (left temporal cortex) and have an abnormal response to language in the temporal cortex that worsens with age compared with typically developing children that show the opposite trend (Eyler, Pierce, & Courchesne, 2012).

When children with ASD reach ages 5 to 6, their brain growth becomes abnormally slow or arrested, reaching normal size, with possible decline in volume and size as individuals continue to age (Courchesne, 2011). In the third phase of pathological brain development between pre-adolescence to adulthood the anatomic pathology of autism continues to change as individuals age with decreases in volume and neuron numbers in the amygdala, decreased neuron numbers in the fusiform gyrus, in neuron size in the cerebrum and cerebellum, and thinning in the corpus callosum and cortical regions (Courchesne, Campbell, & Solso, 2011).

When Do the Impairments Occur?

When children have more than one syndrome, such as ASD with mental retardation, tuberous sclerosis complex, or a related disorder such as Rett or Angelman syndrome, the disorder is likely to be manifested by the first trimester (Coleman & Betancur, 2005). For some disorders—such as tuberous sclerosis, where 43% to 86% of individuals have ASD—there may be an underlying disease process that results in autistic symptoms that occurs from the first trimester. However, a susceptible gene for autism may lie in close proximity to a tuberous sclerosis gene and is triggered along with tuberous sclerosis (Rutter, 2005). Certain environmental factors associated with autism, such as rubella infection, ethanol, thalidomide, and valprioc acid for seizures, affect the fetus in the first trimester (Rodier, 2011).

It is the second trimester, or the period of time most associated with brain development, that is associated with neuronal organization and the disordered development in ASD (Coleman & Betancur, 2005; Minshew et al., 2011). The cortex looks different during the second trimester compared with typical brain development (Courchesne, 2011). “Autism is undeniably due to abnormal brain development beginning in early life” (Courchesne, Webb, & Schumann, 2011, p. 611). The implication of the early brain overgrowth is that it occurs at a time when language is typically expanding and consolidating, and this is not happening for young children with ASD. This continued growth of circuitry occurs when there should be pruning and stabilization that interferes with social communication (Courchesne, 2011).

Environmental Toxins

“The developing brain is particularly vulnerable to environmental toxins. The blood–brain barrier of the developing brain is not fully formed, and it is more permeable to toxins than is the mature brain. The rapid growth of the brain during the second trimester of fetal development is followed by neuronal migration, differentiation, proliferation, and pruning throughout early childhood. Growing cells are more vulnerable to toxins, and the brain forms over a longer period than do other organs. ” (Lanphear, 2015, p. 213). Research on the relationship between environmental toxins and autism spectrum disorders is the focus of CHARGE (CHildhood Autism Risks from Genetics and the Environment) located at the UC Davis MIND Institute in Sacramento. Although no definitive factors have been found, research has revealed a greater risk for the following: advanced parental age; children of recent immigrants; some infections during pregnancy; living close to a freeway; exposure to pesticides, lead, mercury, and other toxic metals; medically related exposures; dietary-related toxicants; and certain air pollutants (Hertz-Picciotto, 2011; Rossignol & Frye, 2012).

“The environmental factors identified thus far account for a very small proportion of autism cases, but that does not diminish the importance of their contribution to our understanding of ASDs” (Rodier, 2011, p. 863). One of the most widely known possible toxins (because of several publications in the popular press) is the measles, mumps, and rubella (MMR) vaccine. The following sequence of events describes the rise and fall of the attribution of cause for the symptoms of autism related to the MMR vaccine.

Evolution of the Attribution of Cause to the MMR Vaccine

- In 1996, a lawyer hired Andrew Wakefield, a British gastroenterologist reporting an increase in inflammatory bowel disease, to conduct research on behalf of families having children with autism to support litigation against the MMR vaccine.
- In 1998, a study published in *The Lancet* (a British medical journal) reported there might be a connection between the MMR vaccine and autism. It reported that 12 children with autism spectrum disorder given this vaccine developed inflammation of the intestines.
- In 1998, the Medical Research Council of Britain set up a panel to study the link and found no association between vaccines and autism.
- In 1999, a study revealed that the preservative thimerosal, a mercury-containing compound present in many vaccines, caused several infants to have levels of mercury in their blood that exceeded the guidelines recommended by the Environmental Protection Agency (EPA). The CDC recommended that thimerosal be removed from the vaccine, even though “there is no data or evidence of any harm caused by the level of exposure,” but it is perceived

as safer by others. Consequently, the preservative was changed.

- In 2004, 10 of 13 scientists who produced the 1998 study retracted their conclusions. "In a statement to be published in the March 6 issue of *The Lancet*, a British medical journal, the researchers concede that they did not have enough evidence at the time to tie the measles, mumps, and rubella vaccine, known as MMR, to the autism cases. The study has been blamed for a sharp drop in the number of British children being vaccinated and the outbreaks of measles" (O'Connor, 2004).
- In July 2006, the *British Times* published that Britain was in the grip of a measles epidemic. In March the first child in 14 years was killed by the virus and there were clusters of infections in Surrey and Yorkshire that propelled the number of confirmed cases that year to 449, the largest number since the MMR vaccine was introduced in 1988.
- In May 2010, Andrew Wakefield had his license revoked by Britain's medical council.
- In January 2011, citing information obtained by journalist Brian Deer, the *British Medical Journal* stated that Wakefield's data was fraudulent. Andrew Wakefield appeared on several television stations in the United States and stated that there was no fraud from him, only from Brian Deer, who he called a "hit man."

Research on the MMR vaccine has not supported any major role in the manifestation of ASD (Hertz-Picciotto, 2011). "It may be concluded that it is quite implausible that MMR is generally associated with a substantially increased risk for autism" (Rutter, 2005, p. 435). Researchers who evaluated the effects of the MMR vaccine in Quebec, Canada, when there was a 93% uptake of the vaccine during the 11-year period studied, found no association between the MMR uptake and PDD rates either when one dose was administered at 12 months of age or when two doses were administered at 12 and 18 months of age (Fombonne, Zakarian, Bennett, Meng, & McLean-Heywood, 2006). There was no significant difference between the rate of dosing and the increase in PDD prevalence (Fombonne, Zarakarian, Bennett, Meng, & McLean-Heywood, 2006). The cells from a subset of the young children with PDD in Quebec who received the two-dose schedule of the MMR vaccine were compared with a control group, and there was no significant difference in the anti-MV antibody titers (D'Souza, Fombonne, & Ward, 2006). The authors conclude, "Our data, together with the epidemiological evidence, demonstrate that arguments against vaccinating children with MMR because of fear of ASD are not defensible on scientific grounds" (D'Souza et al., 2006, p. 1674). Nonetheless, if parents want to take precautions regarding the MMR vaccine, they can ask for each of the vaccines separately, they can request that the titers for the antibodies in their child's system be obtained prior to receiving a booster shot in order to determine if a booster is necessary, and they can request preservative-free vaccines.

Physiological Interventions

Medication Treatment

Treating the behaviors associated with autism spectrum disorders with drugs or medication has been occurring since individuals were placed in the care of the medical community in hospitals and institutions. Only those professionals who are trained with medical degrees, such as a medical doctor (MD) or a psychiatrist, can prescribe medication. An Internet survey of 552 parents of children with autism revealed that 52% reported that their child was currently using medication (Green et al., 2006). Survey respondents of 195 parents with 2- to 8-year-olds involved in early intervention in Indiana revealed that 27.7% indicated involvement in medical treatment (Hume, Bellini, & Pratt, 2005).

Drugs that have been developed to treat other psychological (schizophrenia, depression) and behavioral [attention deficit hyperactivity disorder (ADHD)] symptoms have been used with individuals with ASD as a means of managing attention, arousal, aggression, irritability, and self-injury. It is important to note that the fundamental biological mechanisms underlying ASD and ADHD may be quite different (Doyle & McDougle, 2012). Based on double-blind, placebo-controlled studies, the Food and Drug Administration (FDA) has approved the use of risperidone (Risperdal) in children, ages 5 to 16, diagnosed with autism with irritability (Blankenship, Erickson, Stigler, Posey, & McDougle, 2011; Doyle & McDougle, 2012). Common side effects of risperidone include increased appetite and weight gain, tremors, dizziness, drowsiness, and sedation (McCracken, 2011). Double-blind, placebo-controlled studies also have revealed benefits of serotonin reuptake inhibitors (e.g., Zoloft, Luvox) for addressing repetitive behavior (Blankenship et al., 2011). These drugs are better tolerated in adolescents and adults than they are in children (Doyle & McDougle, 2012). Psychostimulants (e.g., Ritalin) are less efficacious in children with PDD than in typical children with ADHD and cause more adverse effects (Blankenship et al., 2011); however, they continue to be prescribed for children with ASD (McCracken, 2011) (see Table 1.2).

> To date, double-blind placebo-controlled studies have not identified a drug with consistent beneficial effects on the social or communication impairments of autism. (Blankenship et al., 2011, p. 1196)

Information on the drugs reported used with their children with ASD from 27,000 parents has been collected since 1967 by the Autism Research Institute (ARI), founded by Bernard Rimland. Parents volunteer the information about the prescriptions used and their opinions about the effectiveness (Pangborn & Baker, 2005). It is clear from the placebo studies described in this chapter that parents are more likely to report positive effects even if they are not demonstrated by research.

Table 1.2 was modified to include only drug interventions (Autism Research Institute, 2009). The variety of drugs used is notable. The highest number of cases reported used Ritalin, with only 29% of parents indicating that there was an improvement. It is notable that several of the drugs used where parents have reported that their child got better for greater than 50% of the time were those used to control seizures (see Table 1.2).

Sandler and Bodfish (2000) conducted a placebo-controlled study and found no difference between a placebo and a single dose of secretin. They reported an interesting finding that 75% of the parents continued to believe in the benefits of secretin even after being informed about the study results. In spite of this outcome, the researchers stated that we should strive to practice evidence-based medicine (Sandler & Bodfish, 2000). In their review of 17 quantitative studies, 13 of which were randomized, double-blind, and placebo controlled, Esch and Carr (2004) report that only one study found any evidence of a causal relationship between secretin and changes in the symptoms of the 600 participating individuals with autism spectrum disorders. These authors discuss that parents may elect secretin treatment perhaps because of stress due to the pervasiveness of their child's symptoms, a high degree of motivation to try any promising treatment, and hope for a drug made from a substance naturally found in the human body that may seem safe (Esch & Carr, 2004).

TABLE 1.2 Parent ratings of behavioral effects of biomedical interventions

The parents of autistic children represent a vast and important reservoir of information on the benefits—and adverse effects—of the large variety of drugs and other interventions that have been tried with their children. Since 1967, the Autism Research Institute has been collecting parent ratings of the usefulness of the many interventions tried on their autistic children.

The following data have been collected from the more than 27,500 parents who have completed our questionnaires designed to collect such information. For the purposes of the present table, the parents' responses on a 6-point scale have been combined into three categories: "made worse" (ratings 1 and 2), "no effect" (ratings 3 and 4), and "made better" (ratings 5 and 6).

	Parent Ratings			
Drugs	**Got Worse[A] (%)**	**No Effect (%)**	**Got Better (%)**	**Number of Cases[B]**
Actos	19	60	21	140
Aderall	43	26	31	894
Amphetamine	47	28	25	1,355
Amafranil	32	39	29	440
Antibiotics	33	50	18	2,507
Antifungals[C]				
Diflucan	5	34	62	1,214
Nystatin	5	43	52	1,969
Atarax	26	53	21	543
Benadryl	24	50	26	3,230
Beta Blocker	18	51	31	306
Buspar	29	42	28	431
Chloral				
Hydrate	42	39	19	498
Clonidine	22	32	46	1,658
Clozapine	38	43	19	170
Cogentin	20	53	27	198
Cylert	45	35	19	634
Depakene[D]				
Behavior	25	44	31	1,146
Desipramine	34	35	32	95

	Parent Ratings			
Drugs	**Got Worse[A] (%)**	**No Effect (%)**	**Got Better (%)**	**Number of Cases[B]**
Dilantin[D]				
Behavior	28	49	23	1,127
Seizures	16	37	47	454
Fenfluramine	21	52	27	483
Haldol	38	28	34	1,222
IVIG	7	39	54	142
Klonapin[D]				
Behavior	31	40	29	270
Seizures	29	55	16	86
Lithium	22	48	31	515
Luvox	31	37	32	251
Mellarll	29	38	33	2,108
Mysoline[D]				
Behavior	41	46	13	156
Seizures	21	55	24	85
Naltrexone	18	49	33	350
Low dose				
Naltrexone	11	52	38	190
Paxil	34	32	35	471
Behavior	48	37	16	1,125
Seizures	18	44	38	543

	Parent Ratings			
Drugs	**Got Worse[A] (%)**	**No Effect (%)**	**Got Better (%)**	**Number of Cases[B]**
Prolixin	30	41	28	109
Prozac	33	32	35	1,391
Risperidal	21	26	54	1,216
Ritalin	45	26	29	4,256
Secretin				
Intravenous	7	50	43	597
Transdermal	9	56	35	257
Stelazine	29	45	26	437
Steroids	34	30	36	204
Tegretol[D]				
Behavior	25	45	30	1,556
Seizures	14	33	53	872
Thorazine	36	40	24	945
Tofranil	30	38	32	785
Valium	35	42	24	895
Valtrex	8	42	50	238
Zarontin[D]				
Behavior	34	48	18	164
Seizures	20	55	25	125
Zoloft	35	33	31	579

A. "Worse" refers only to worse behavior. Drugs, but not nutrients, typically also cause physical problems if used long term. B. The number of cases is cumulative over several decades, so the number does not reflect current usage levels (e.g., Haldol is now seldom used). C. Antifungal drugs and chelation are used selectively, where evidence indicates they are needed. D. Seizure drugs: behavior effects other than on seizures, effects on seizures.

Source: Adapted from *Summary of Biomedical Treatments for Autism.* Autism Research Institute Publication 34/March, 2009. Used with permission.

Diets

In a study on the maternally reported incidence of asthma and allergies of 560 children with ASD and 391 typical children, the researchers concluded that although there were no overall differences by group, reported food allergies were significantly associated with ASD (Lyall, Van de Water, Ashwood, & Hertz-Picciotto, 2015). A study of 960 children from CHARGE revealed that gastrointestinal (GI) problems affected children with ASD and developmental disabilities significantly more than typical control children (Chaidez, Hansen, & Hertz-Picciotto, 2014). Examples of reported GI problems for children with ASD include: frequent abdominal pain, constipation or pain on stooling, gaseousness, and diarrhea. In this sample, when parents reported that the child ate a restricted diet, they stated that this was child selected or child preference for only some foods rather than a choice made by parents (Chaidez et al., 2014). However, placing a child on a special diet is an intervention used by parents.

Special diets are classified with a group of treatments considered as complementary and alternative medical (CAM) treatments (Akins, Krakowiak, Angkustsiri, Hertz-Picciotto, & Hansen, 2014; Hyman & Levy, 2011). Parent surveys have revealed that 50% of the 121 parents who had children in applied behavior analysis treatment programs also tried elimination diets (Smith & Antolovich, 2000), 27% of the 552 parents surveyed through the Internet indicated implementing a special diet (Green et al., 2006), and 24.7% of the 453 CHARGE parents of children with ASD reported using dietary supplements as the most common form of CAM followed by a special (GFCF) diet (18.3%) (Akins et al., 2014). It is advised that any special diet be supervised by a physician with knowledge about nutrition and the side effects of eliminating foods from the diet (Pangborn & Baker, 2005) and follow the consensus guidelines developed by medical societies for the management of common gastrointestinal symptoms (Buie et al., 2010). Although the neurobiological mechanisms are unclear, there are neurotransmitters found in the brain that also function in the gut (Chaidez et al., 2014).

There is a theory that some individuals with autism spectrum disorders have a "leaky gut," in which opiate peptides typically digested are passed through the stomach and travel to parts of the body, including the brain, resulting in discomfort and the display of the behaviors associated with ASD (Hyman & Levy, 2011). Gluten, a common wheat product found in breads and cereals, is the main culprit for these events, and similar to celiac's disease, gluten is thought to be undigested. Casein from milk products also breaks down into a similar peptide (casomorphine) as gluten (gliadnomorphins) (Lewis, 2002). Some of the peptides obtained from gluten and casein are very similar to those endorphins found in the brain. These opioid peptides act as neuroregulators.

Shattock and Whiteley (2000), who work at the University of Sunderland in the United Kingdom, have designed a protocol for the removal of casein and gluten from the diet along with the promotion of enzyme activity from dietary supplements. In spite of the fact that it is unlikely that an early developmental disorder such as ASD can be caused by limited experience with gluten (Pavone & Ruggieri, 2005), many families of children with autism spectrum disorders have tried a gluten-free and casein-free (GFCF) diet. In some situations the reported changes in autism symptoms are great (Lewis, 2002; Seroussi, 2000). However, the children on the diets are typically also receiving educational interventions that may be the actual cause of change in behavior.

A randomized, double-blind, repeated-measures study was conducted on the gluten- and casein-free (GFCF) diet by professionals in the College of Nursing of the University of Florida (Elder et al., 2006). Fifteen children who were diagnosed using established assessment tools were given either the GFCF diet or a placebo for 12 weeks. Dependent measures included urinary peptide measures, language samples, and parent and child behaviors. The results indicated that there were no significant differences between the groups on any measures (Elder et al., 2006). However, parents of seven children reported improvements, and nine parents elected to maintain a GFCF diet, even though they were informed that there was no empirical support for the diet (Elder et al., 2006). A review of randomized, controlled trials involving GFCF diets revealed only one study that reported a reduction in the behaviors associated with ASD (Millward et al., 2004). Kern and colleagues (Kern, Miller, Evans, & Trivedi, 2002) used a double-blind, placebo-controlled study in children with ASD and found positive results only for those children with chronic, active diarrhea; they suggest that such children may represent a subtype of autism.

> Well-designed trials are needed to develop an evidence base for optimal diagnostic and treatment strategies to manage gastrointestinal disorders in children with ASDs. (Buie et al., 2010, p. S19)

Some families report it is costly and time-consuming to organize an alternative diet for one child and that children often react badly to the initial withdrawal of their favorite foods (Elder et al., 2006). In addition, some children with ASD may be selective in their food preferences, further limiting their intake (Williams & Foxx, 2007). However, changing a child's diet is an intervention where parents may feel they can make a contribution. By controlling the food their child eats, parents may feel like they are taking action to address the characteristics of ASD.

Sensory Activities

Difficulties with sensory input have long been associated with autism spectrum disorders. Early versions of the DSM listed sensory impairments as one of the diagnostic criteria (DSM-III), and these criteria are included again in the DSM-5. Anecdotal reports of both hyper- and hyposensitivity to environmental stimuli are common (Anzalone & Williamson, 2000) with more evidence of hypo- than hyper-responsiveness reported (Rogers & Ozonoff, 2005). Researchers in London who have exposed information about brain synaptic activity and brain size into an artificial neural network modeling predict that the earliest developmental symptoms of autism may be sensory and motor (Thomas, Knowland, & Karmiloff-Smith, 2011). Descriptions of individuals with ASD who cover their ears when music is played or react to a generally considered light touch or mild odor as if it is painful are considered hypersensitive (Grandin, 1992; O'Neill & Jones, 1997). High-functioning individuals with ASD report difficulty filtering out background noises during conversations (Baranek, Little, Parham, Ausderau, & Sabatos-DeVito, 2014). Individuals who act as though they are deaf or are nonreactive when a fire alarm goes off are considered hyposensitive (Anzalone & Williamson, 2000; Baranek, 2002).

There has been increasing focus on the repetitive and stereotypic behaviors of young children with and at risk for ASD, one aspect of the main criteria for classifying ASD in the DSM-5. Compared with typically developing toddlers between 14 and 21 months of age, those with ASD had significantly high frequencies of repetitive behavior with objects (Barber, Wetherby, & Chambers, 2012). Wolff and colleagues (2014) also found significantly higher rates of repetitive behaviors across subtypes for high-risk toddlers with ASD in their longitudinal study and conclude that a broad range of repetitive behaviors are highly elevated as early as 12 months of age for those children who go on to develop ASD. When stereotypic motor mannerisms and repetitive manipulation of objects in 12-month-olds at low and high risk for ASD were evaluated in another study, the high-risk group showed significantly more stereotyped motor mannerism and repetitive object manipulation compared with a low-risk group (Elison et al., 2014). These researchers recommend targeting the assessment of repetitive behavior during infancy, and others recommend early intervention as essential in addressing repetitive behavior in young children (Boyd & Wakeford, 2016). Although evident in infancy for some individuals with ASD, difficulties with sensory stimuli can be found in adolescents and adults with ASD (Howe & Stagg, 2016).

Baranek and colleagues (2014) describe four distinct behavioral patterns, or features, that are most commonly reported. These four features are the focus of the Sensory Experience Questionnaire that Baranek developed and include: (1) hypersensitivity; (2) hyposensitivity; (3) sensory interests, repetitions, and seeking behaviors, or the repetitive or stereotypic behaviors exhibited by some individuals (e.g., waving fingers in front of the eyes, body rocking); and (4) enhanced perception that may support identified gifts and talents such as playing piano music by ear. It is not uncommon for individuals with ASD to experience multiple features and with varying patterns of responses. In order to determine any distinct patterns of features, Ausderau and colleagues (2014) conducted an analysis on the results of the Sensory Experience Questionnaire-3 (Baranek, 2009), the Social Responsiveness Scale (Constantino, 2005), and a Background Information Questionnaire for children with ASD ages 2 to 12 across two time periods (*n* = 1294 for time 1 and *n* = 884 for time 2). The results were four distinct clusters that were stable over time: (1) mild subtype—scored low on all sensory patterns (29% of sample); (2) extreme-mixed subtype with high scores for all four sensory patterns (17% of the sample); (3) sensitive-distressed subtype—scored close to the mean on all subtypes with lower scores on hypo-responsiveness and SIRS and higher scores on hyper-responsiveness and EP (28% of the sample); and (4) attenuated-preoccupied subtype—with the opposite pattern of higher scores for hyposensitivity and SIRS (17% of the sample) (Ausderau et al., 2014). The authors suggest future research to determine if the subtypes remain beyond the 1-year time period used in this study.

The percentage of individuals with ASD who display these atypical reactions to sensory stimuli remains unknown and is estimated to be between 42% and 88% (Baranek, 2002; Baranek et al., 2014). Research with 104 individuals diagnosed with autism between 3 and 56 years of age found that results of the Sensory Profile correlated with the results of the severity score on the Childhood Autism Rating Scale (Schopler, Reichler, & Rochen Renner, 1998) for young children but not for adolescents and adults, indicating that there was an apparent lessening of abnormal sensory processing (Kern et al., 2007). A review of the research using strategies based on behavior analysis to increase variability in those individuals with ASD displaying repetitive behavior identified 14 studies completed between 2000 and 2013 (Wolfe, Slocum, & Kunnavatana, 2014).

There are several theories of atypical physiology and sensory differences in ASD. One proposal is that there are difficulties simultaneously filtering and processing sensory information from multiple modalities or with multisensory integration and perception (MSI) (Baranek et al., 2014). In order to better understand the physiological responses to sensory stimuli by individuals with ASD, researchers have used electroencephalogram (EEG) measurements of the brain (Donkers et al., 2015) and electrocardiogram (ECG) measurements of the heart (Schaaf, Benvides, Leiby, & Sendecki, 2015) with 4- to 12-year-olds with ASD. Some researchers have evaluated the sensory thresholds levels when individuals with ASD perceive sensory stimuli; however, studies have not revealed a consistent lowered threshold. Another hypothesis is that there are problems with the brain's capacity to regulate sensitivity to stimuli or with sensory gating. "Further studies are needed to unravel the complexities presented in physiological studies of children with ASD, particularly how parent-report and behavioral measures of sensory response patterns are associated with physiological findings" (Baranek et al., 2014, p. 387).

Theorizing about the interactions between the environment and the individual's nervous and sensory systems, and suggesting interventions based on these theories, has been considered the realm of occupational therapy (OT) (Miller-Kuhaneck, 2004; Wakeford & Baranek, 2011). Occupational therapists study physiology and neurology and have engaged in debates regarding theories that describe the characteristics of autism spectrum disorders (O'Neill & Jones, 1997; Rogers & Ozonoff, 2005). In 2004 a committee of occupational therapists met to define common terms used in the field and defined *sensory processing disorder* as "a neurological disorder that causes the brain to misunderstand information it receives from the senses" (Arnwine, 2011, p. 1). In general, occupational therapy–based activities are child-directed and are designed to promote the development of skills in the context of work, play, and adaptive behavior (Arnwine, 2011; Dawson & Watling, 2000).

Sensory Considerations 1.1

Sensory Integration Therapy (SIT)

Sensory integration therapy is based on the theory developed in the 1970s by Jean Ayres (1972), who worked with individuals with learning disabilities (Dawson & Watling, 2000). Sensory integration theory is based on assumptions about the ways in which sensations are organized, processed, and integrated within the central nervous system and that activities can be help result an adaptive behavioral response (Boyd & Wakeford, 2016). Sensory integration therapy is an individual therapy that requires specialized training with an aim to elicit child engagement through "just right challenges" (Baranek et al., 2014).

The goal of the sensory integrative process is to address the following four As: (1) arousal level, (2) attention to the environment, (3) affect, and (4) action, or engagement in adaptive, goal-directed behavior (Anzalone & Williamson, 2000). The therapy aims to enhance sensory integration and praxis abilities in order to induce broader social participation and adaptive outcomes (Baranek et al., 2014).

Three studies obtaining information from parent surveys indicate a high percentage of the use of sensory integration therapy: 56% of those enrolled in intensive behavior analytic treatment (Smith & Antolovich, 2000), 40% from participation in early intervention programs (Hume et al., 2005), and 38.2% from the Internet survey (Green et al., 2006). Intervention strategies based on sensory integration theory consist of planned sensory experiences such as swinging, deep-pressure touch, and tactile stimulation.

Schaaf and colleagues (2014) completed a randomized trial study with a group receiving an additional 30 hours of sensory integration therapy (n = 17) compared with a treatment-as-usual group (n = 15). Results revealed significant differences for progress made on established sensory goals using Goal Attainment Scaling for the SI group and significantly less assistance needed for self-care and significantly better scores for socialization according to caregiver report (Schaaf, 2014). The publication of the randomized trial study by Schaaf and colleagues was commended in a letter to the editor along with recommendations to improve the rigor of the design in future research (Ashburner, Rodger, Ziviani, & Hinder, 2014). Suggestions for improving the quality of the research included the use of observational measures in addition to parent report only, ensuring that there is consistency in dosage (the SI group received 30 more hours of intervention), and using an active treatment sensory based comparison group (Ashburner et al., 2014).

Deep-pressure touch has been reported by Temple Grandin, a high-profile adult with autism, as a helpful strategy for calming down (Grandin, 1992). She reports that she created a Hug Machine that she used to apply deep pressure when desired. Deep pressure from the Hug Machine was evaluated for five children with autism—on galvanic skin response (GSR) and parent ratings on created subscales from items off the Conners Parent Rating Scale—compared with seven children who received no deep pressure or a placebo control (Edelson, Edelson, Kerr, & Grandin, 1999).

Based on the reported benefits of deep pressure, occupational therapists have recommended that children with ASD wear vests with weights in them to assist with focus and attention to task. Two studies using alternative treatment designs evaluated the effect of weighted vests with children with ASD (Cox, Gast, Luscre, & Ayes, 2009; Reichow, Barton, Neely-Sewell, Good, & Wolery, 2010) and found that there was no difference between conditions and no functional relationship between wearing the weighted vests during classroom activities and attention to task or engagement.

The effects of touch or massage by parents at bedtime was evaluated for the effects on sleep problems and social relatedness, stereotypic behavior, and on-task behavior during bimonthly observations of play at preschool (Escalona, Field, Singer-Strunck, Cullen, & Hartshorn, 2001). The 10 participants in the experimental group slept better and were comparatively more attentive with less stereotypic behavior when they received massages. The authors conclude that the increase in attentiveness could be due to getting better sleep or enhanced parasympathetic activity (Escalona et al., 2001). Eleven children who received touch therapy composed of rubbing with moderate pressure and smooth strokes for 15 minutes per day 2 days per week for 4 weeks were observed less frequently as orienting to irrelevant sounds and exhibiting stereotypic behaviors compared to an attention control group. There were no differences in off-task behavior or touch aversion between the two groups (Field et al., 1997).

Occupational therapists have recommended the use of a ball or specially designed chair for sitting in order to assist in maintaining attention or arousal. Schilling and Schwartz (2004) evaluated the use of such therapy balls with young children with ASD and concluded that there was an improvement in in-seat behavior and engagement for the four participants in their study. Sensory activities that modulate the four target areas can be considered a sensory diet (Anzalone & Williamson, 2000). The purpose of a sensory diet is to help the individual to attain and maintain optimal arousal states or to provide sensory input that is sufficiently consistent and intensive to change sensory processing capacities (Wilbarger, 1995). Similar to a nutritional diet, a sensory diet involves planning for someone's individual needs (Wilbarger, 1995). It is recommended that activities be implemented throughout the day with sensory tune-ups scheduled at key times (Wilbarger, 1995). Wilbarger and Wilbarger (1991) described a strategy called the sensory summation technique that involves a combination of brushing the arms, back, and legs rigorously with a surgical scrub brush followed by 10 gentle joint compressions to the arm and leg joints and concluding with sensory input to the fingers and toes. This procedure, referred to as the Wilbarger Protocol, has been recommended by occupational therapists to be implemented by public school preschool teachers multiple times throughout the day.

A systematic review of the research on sensory-based treatments for children with disabilities found 30 total studies, half group designs and half single-case designs, used to evaluate a variety of focused interventions such as weighted vests and more comprehensive interventions (Barton, Reichow, Schnitz, Smith & Sherlock, 2015). The authors conclude that the research designs used are frequently weak with considerable heterogeneity of the measure of implementation and that there is currently insufficient evidence to support the use of sensory-based treatments. They also found a substantial number of studies that did not support the use of sensory-based interventions with outcomes revealing no difference in comparison conditions or groups or behavioral strategies as more effective (e.g., Sniezyk & Zane, 2015). They also comment that there is a lack of adherence to underlying therapeutic principles across the sensory integration intervention research and call for documentation of positive neurological effects of sensory-based interventions prior to conducting additional research (Barton et al., 2015).

Barton and colleagues (2015) also comment that, in spite of the lack of evidence, the use of sensory based strategies remain common place in public schools. It would be important for teachers and occupational therapists using such strategies to evaluate the outcome for individuals with ASD. A study conducted by a preschool teacher where sensory diets or activities were compared to an attention control condition in a public school classroom provides an example (Bonggat & Hall, 2010). These interventions were evaluated using an alternative treatment design on the effects of on-task behavior during the scheduled activities that followed the intervention sessions. The results indicated no difference for the sensory diet or attention control condition on the on-task behaviors on the participants (Bonggat & Hall, 2010). Data was collected by the preschool teacher of the classroom demonstrating how educators can evaluate the effects of strategies recommended by occupational therapists.

"The dearth of efficacy studies warrants that practitioners select and monitor interventions for sensory processing problems carefully and target meaningful outcomes (e.g., functional activities, social participation etc.) that are specific to each individual with ASD" (Baranek et al., 2014, p. 396). Recent policies that emphasize the use of evidence-based practices have resulted in a critique of current practices used by occupational therapists and a call for empirical research on sensory-based interventions by school psychologists (Shaw, 2002), special educators (Goldstein, 2000), and leaders in the field of occupational therapy (Wakeford & Baranek, 2011; Ottenbacher, Tickle-Degnen, & Hasselkus, 2002). Occupational therapists are required to complete assessments, design interventions, and complete intervention reviews as part of evidence-based practices (Wakeford & Baranek, 2011). Schaaf and Lane (2015) make several conclusions in their paper on best practice protocol for assessment of sensory features of individuals with ASD that include conducting research that directly relates the sensory features to the core clinical symptoms of ASD, focusing research on determining if there is a distinct profile of multisensory integration impairment, and expanding outcome measures beyond parent/proxy report measures. They also recommend an inter-professional approach to treatment planning that includes professionals from diverse disciplines such as psychologists, educators, and occupational therapists (Schaaf & Lane, 2015).

Working in Collaboration with Occupational Therapists

It is clear that our colleagues who work as geneticists and neurologists will be busy trying to find the pieces of the puzzle in the forms of genes and brain functions that result in the behaviors classified as autism spectrum disorders. The creation of a pharmacological intervention designed specifically for autism is a future prospect. In addition, research is needed from nutritionists and occupational therapists to determine the effects of individually designed diets on physiological changes that affect learning.

In the meantime, educators will be increasingly required to provide effective instruction to individuals classified with autism spectrum disorders. The remainder of this book will focus on strategies that can be used by educators, with comments regarding the research evidence, or lack thereof, in support of the strategies. When the term **autism spectrum disorders** is used, it will mean all individuals classified using the DSM-5 criteria, which includes those previously described as pervasive developmental disorder and Asperger syndrome.

In addition to using effective and evidence-based strategies, educators can be most successful if they work in collaboration with parents and specialists. Parents are typically the interface between specialists such as physicians

1.2

IN THEIR WORDS

Janinne Karahalios,
MS, OTR/L Occupational Therapist

Collaboration in a Public School Setting

As an occupational therapist in the school setting, my goal is to support the creation of an environment where children with autism spectrum disorders (ASD) can learn how to fulfill their roles as "student" with as much independence as possible. I encourage active participation in purposeful and meaningful tasks to promote the development of self-care, self-regulation, and motor skills. In order to achieve this goal I work directly with students and actively collaborate with team members in a consistent and effective manner.

I have found communication to be essential in achieving the consistency necessary for successful programming for children with ASD. It is important that parents, teachers, and other service providers share a vision of the student's future and develop a common path to achieve the desired results. The individualized education program (IEP) must represent this vision, and each team member should be familiar with all goals because goals are addressed across multiple settings throughout the day, not solely in individual settings. Students will not meet the goals that fall in the realm of occupational therapy (OT) if they are addressed only during an OT session. Occupational therapists rely on teachers, parents, and paraprofessionals to carry out their recommendations each time the opportunity presents itself within the context of the child's natural environment. It is similarly important for occupational therapists to address cross-disciplinary goals when given the opportunity.

Participation in all school settings—the classroom, recess, physical education, music, and art—is vital for the child with ASD to fulfill his or her role as "student." Occupational therapists believe that many children with ASD demonstrate differences in sensory processing patterns. Occupational therapists increase the awareness of the impact sensory input may have on a student's adaptive behavior and functional motor skills within each of these environments. A child's heightened responsiveness to sensory experiences can increase anxiety, especially in new situations. Provision of predictability, order, and routine can prevent "fight or flight" reactions that sometimes result in inappropriate behaviors. Visual schedules, first-then boards, use of visual and auditory timers, and creation of social stories are examples of strategies that can be used to ease anxiety during stressful situations. Modification of sensory experiences, such as allowing for use of tools when initially involved in messy play and the use of sound-dampening headphones when attending a noisy assembly, can make the experiences tolerable for a student with ASD. These accommodations can be slowly and systematically altered to increase the child's tolerance to such activities. Occupational therapists also help create dressing and feeding routines to be practiced daily during toileting, snack, and lunch times to increase independence in these skills.

Occupational therapists also provide suggestions for providing a sensory-friendly environment. Recommendations might include: offering a "quiet corner" for de-escalation; avoidance of seating in high-traffic areas; using rugs or carpets to absorb environmental noise; eliminating glare from fluorescent lighting; providing visual organization to clearly define space; and creating opportunities for movement activities, such as jumping, climbing, swinging, and running.

Each team member brings unique knowledge, skills, and experience to the educational program. Effective communication between team members and consistent implementation of agreed-upon strategies and programs will assist students with ASD to gain skills to navigate through learning and life and to make strides toward independence.

and nutritionists and the educator. Information regarding parents' choice to use medication or a special diet would be important for educators to be aware of, and good communication with families is an essential means of obtaining this information. It would also be important for families to learn about any noticeable changes in behavior that are observed by educators following implementation of a diet or medication regime. Certainly families would want to know if their children appear to be too sleepy to attend to an activity or lesson or if they are displaying an increase in challenging behaviors.

Because occupational therapists often work in public schools, it is likely that educators will communicate directly and work collaboratively with the assigned specialist. The occupational therapist can provide suggestions for curriculum modifications that take into account any preferences for, or sensitivities to, sensory stimuli. Efforts can be made to ensure that any suggested interventions are individualized for each student and that some form of data is obtained to determine the effectiveness of any specifically designed strategy. Janinne Karahalios is an occupational therapist who works with individuals with autism who attend public schools in Connecticut. She holds the perspective that it is important to work with educators in the context of the classroom to achieve maximum results (see In Their Words 1.2).

A focus on sensory considerations will be addressed for all topics throughout this book. Look for the **Sensory Considerations** section highlighted in each chapter.

SUGGESTIONS FOR DISCUSSION

1. Discuss the evidence for a genetic influence on autism spectrum disorders. From your experience, do you think there is a broad autism phenotype with characteristics displayed by family members of an individual with ASD?
2. Identify the changes to the diagnostic criteria with the *Diagnostic and Statistical Manual*-5 (DSM-5) compared with the DSM-IV. What do you think about not having a separate category for Asperger disorder?
3. Engage in a debate with one side arguing for an increase in the incidence of ASD due to the reported prevalence rates within the previous 10 years and the other side arguing for other factors contributing to the reported increase in prevalence.
4. What is the argument for a gluten- and casein-free diet, and why do you think some parents elect to place their child on this diet?
5. Describe the aim of strategies and activities recommended by occupational therapists for children with autism spectrum disorders.
6. Discuss why there is so little research published on the effectiveness of sensory-based strategies and activities.
7. Identify the strengths and limitations of the physiological approach to address the (a) occurrence and (b) characteristics of autism spectrum disorders.

RESOURCES

Books

Amaral, D. G., Dawson, G., & Geschwind, D. H. (2011). *Autism spectrum disorders*. New York: Oxford University Press.

Coleman, M. (2005). *The neurology of autism*. New York: Oxford University Press.

Grandin, T., & Panek, R. (2013). *The autistic brain: Helping different kinds of minds succeed*. New York: Mariner Books.

Volkmar, F. R., Rogers, S. J., Rhea, P., & Pelphrey, K. A. (2014). *Handbook of autism and pervasive developmental disorders (4th edition): Volume 1: Diagnosis, development, and brain mechanisms*. Hoboken, NJ: John Wiley & Sons.

Websites

Autism Society of America

Information about living with autism and how to locate affiliate chapters in each state

Be in CHARGE—Childhood Autism Risks from Genetics and the Environment

The website for CHARGE at the UC Davis MIND institute contains access to publications and to audio and video presentations on topics such as genetic and environmental links to autism

Centers for Disease Control and Prevention

Autism spectrum disorders site contains data on prevalence over time in the United States and for countries outside the Unites States

The American Psychiatric Association

Publishes the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) with criteria for autism spectrum disorder

CHAPTER TWO

Assessment

LEARNING OUTCOMES

At the conclusion of this chapter, the reader should be able to:

- Identify common characteristics of ASD across the three widely used screening instruments for infants and toddlers.
- Explain why the ADOS and ADI-R are considered the gold standard for diagnosing individuals with autism spectrum disorders.
- Describe how a teacher could use one of the assessment tools for educational planning to identify goals for a student with ASD based on the student's areas of strength.
- Provide an example of a curriculum-based assessment and describe how assessment results are used for identifying goals and objectives for individuals with autism spectrum disorders.
- Illustrate how a teacher can set up a classroom system to facilitate the collection of ongoing progress monitoring data.

The form of assessment and the tools used depend on the purpose of the assessment. It is important to use the correct tool for the purpose for which it was intended. Using a screwdriver to put a nail in the wall to hang a picture might actually work, but it is far better to use a hammer for this purpose so that you get accurate results. Using a tool to obtain information for which it was not designed may give you inaccurate results. It is also important that the ethnic and linguistic background of the focal individual is considered when selecting assessment tools. Some tools devise their norms, or ages when behaviors are typically present, by testing the tool in one geographic location or with limited numbers of ethnic groups. Families that have newly arrived in the United States may have very different expectations for the development of certain skills. Items on instruments may be unknown, irrelevant, or contrary to the values for families from specific culturally and linguistically diverse backgrounds. It is the responsibility of the assessor to try to eliminate cultural biases when selecting tools and administering assessments.

This chapter describes the assessment tools designed to obtain information about individuals with autism spectrum disorder (ASD). Tools will be described by purpose and will include: screening instruments, diagnostic assessment tools, curriculum-based assessments, progress monitoring assessment, and program evaluation. The link between assessment outcomes and the planning of educational programs will be emphasized.

Screening Instruments

A **screening** is a brief assessment aimed at identifying those infants and/or children who may be at risk for developmental delays due to differences compared with standard expectations for children of the same age range and cultural background (Losardo & Notari-Syverson, 2001). Screening tools are typically administered widely in order to identify individuals who require further testing. Screening tools are designed to be **sensitive** enough to identify those situations where the young child may be identified with autism spectrum disorder (Zwaigenbaum, 2011). It is also important that the instrument does not incorrectly identify those children not at risk, or that the **specificity** of the instrument is sufficiently accurate (Zwaigenbaum, 2011). The **positive predictive value** (PPV), or the proportion of children identified at risk who actually have the disability, is also a concern for screening developers.

More attention has been paid in recent years to the development and implementation of screening tools so young children can be identified early and so intervention can begin when the greatest outcomes are possible. The American Academy of Pediatrics recommends the administration of ASD-specific screening tools on all children at the 18- and 24-month well-child visits (Cangialose & Allen, 2014; Ibanez, Stone, & Coonrod, 2014). Studies of infant siblings of children diagnosed with ASD who are at greater risk for ASD reveal that there are no differences observed at 6 months of age (Ozonoff et al., 2010; Rozga et al., 2011), but at 12 months of age, infants later diagnosed with autism have significant differences in their gaze to faces and directed vocalizations (Ozonoff et al., 2010); declines in play, communication, and impaired vocal imitation (Rowberry et al., 2015); and lower rates of joint attention and requesting behaviors (Rozga et al., 2011). By 18 months there is a difference in the use of social smiles (Ozonoff et al., 2010). When symptoms appear early, by 12 months of age infants later diagnosed with ASD have "decreases in eye contact, social initiative, joint attention, and emotion sharing as well as a failure to respond to name" (Rogers & Wallace, 2011, p. 1085). Although there is a higher risk of false positives with screening before 18 months of age, most parents would choose the stress associated with a positive screen over missing the opportunity for early intervention, especially because most screening tools identify a disability even if it is not ASD (Barton, Dumont-Mathieu, & Fein, 2012).

As part of the federally funded First Words Project, Amy Wetherby and colleagues (2014) developed a handout titled "16 Gestures by 16 Months (16X16)" to identify a delay in the use of gestures, one of the key delays in infants later diagnosed with ASD. The colorful handout with photographs explains that typical infants display the following gestures: "give" and shake their head by 9 months; reach and raise their arms by 10 months; show and wave by 11 months; open hand, point, and tap by 12 months; clap and blow a kiss by 13 months; point with index finger and "Shhh" gesture by 14 months; head nod, thumbs up, hand up to indicate wait by 15 months, and other gestures such as "high five" by 16 months.

Checklist for Autism in Toddlers (CHAT)

The CHAT (Baron-Cohen, Allen, & Gillberg, 1992) is a nine-item screening tool for autism completed by parents with toddlers as young as 18 months. Five additional items for completion by a general medical practitioner or health visitor are also included (Brock, Jimerson, & Hansen, 2006). Research on the specificity and positive predictive value of the CHAT indicates that these are strengths of this measure (Coonrod & Stone, 2005). Three of the nine items appear to be the best predictors of autism spectrum disorders: lack of gaze monitoring, lack of proto declarative pointing, and lack of pretend play by age 18 months (Baird et al., 2000). A follow-up study of 16,253 18-month-old infants in England who were identified by the CHAT during an initial administration revealed that the initial administration and a repeated screening 1 month later resulted in a predictive value of 75% (Baird et al., 2000).

A *Modified Checklist for Autism in Toddlers* (M-CHAT)™ (Robins, Fein, & Barton, 1999), for use with toddlers between 16 and 30 months of age, was developed and implemented in the United States (Robins, Fein, Barton, & Green, 2001). This instrument contains the nine items from the CHAT and additional items that are more likely to be present in young children older than 16 months. Although more time is needed to evaluate the predictive validity of the instrument, the authors state that the M-CHAT can accurately detect children at risk for autism/pervasive developmental disorder (PDD). Table 2.1 lists the 23 items included in the M-CHAT.

TABLE 2.1 M-CHAT

Please fill out the following about how your child **usually** is. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

1. Does your child enjoy being swung, bounced on your knee, etc.?	Yes	No
2. Does your child take an interest in other children?	Yes	No
3. Does your child like climbing on things, such as up stairs?	Yes	No
4. Does your child enjoy playing peek-a-boo/hide-and-seek?	Yes	No
5. Does your child ever pretend, for example, to talk on the phone or take care of dolls, or pretend other things?	Yes	No
6. Does your child ever use his/her index finger to point, to ask for something?	Yes	No
7. Does your child ever use his/her index finger to point, to indicate interest in something?	Yes	No
8. Can your child play properly with small toys (e.g., cars or bricks) without just mouthing, fiddling, or dropping them?	Yes	No
9. Does your child ever bring objects over to you (parent) to show you something?	Yes	No
10. Does your child look you in the eye for more than a second or two?	Yes	No
11. Does your child ever seem oversensitive to noise? (e.g., plugging ears)	Yes	No
12. Does your child smile in response to your face or your smile?	Yes	No
13. Does your child imitate you? (e.g., you make a face—will your child imitate it?)	Yes	No
14. Does your child respond to his/her name when you call?	Yes	No
15. If you point at a toy across the room, does your child look at it?	Yes	No
16. Does your child walk?	Yes	No
17. Does your child look at things you are looking at?	Yes	No
18. Does your child make unusual finger movements near his/her face?	Yes	No
19. Does your child try to attract your attention to his/her own activity?	Yes	No
20. Have you ever wondered if your child is deaf?	Yes	No
21. Does your child understand what people say?	Yes	No
22. Does your child sometimes stare at nothing or wander with no purpose?	Yes	No
23. Does your child look at your face to check your reaction when faced with something unfamiliar?	Yes	No

Source: Modified Checklist for Autism in Toddlers. D. L. Robins, D. Fein, & M. L. Barton. Used with permission. © 1999 Robins, Fein, & Barton.

Early Screening of Autistic Traits (ESAT)

The ESAT is a 14-item questionnaire that was developed in the Netherlands for identifying young children 16 to 48 months at risk for ASD (Swinkels et al., 2006). Parents are asked to report yes or no to items such as "Can your child play with toys in varied ways (not just fiddling, mouthing or dropping them)?," "When your child expresses his/her feelings, for instance, by crying or smiling, is that mostly on expected and appropriate moments?," and "Is it easy to make eye contact with your child?" The developers found that caregivers other than the parents were more likely to give negative answers (Swinkels et al., 2006).

The ESAT was implemented by a trained child psychologist in a random population of 31,724 children ages 14 to 15 months (Dietz, Swinkels, van Daalen, van Engeland, & Buitelaar, 2006). Eighteen young children with ASD were detected, which is lower than the reported prevalence rate in the Netherlands. The PPV was 25%, with false positives receiving diagnoses of mental retardation, language disorder, and attention deficit hyperactivity disorder (ADHD) (Dietz et al., 2006). None of the identified children were found to have typical development. The ESAT was used as part of a two-stage screening approach that led to earlier detection of ASD, particularly for children with low IQ, in the Netherlands (Osterling et al., 2010).

Infant-Toddler Checklist

The Infant-Toddler Checklist (ITC) is a 24-item tool designed to be completed by caregivers when children are ages 6 to 24 months (Wetherby & Prizant, 2002). This tool is part of an assessment package created by the same authors of the Communication and Social Behavior Scales (CSBS) Developmental Profile. Items are organized under seven categories: emotion and eye gaze, communication, gestures, sounds, words, understanding, and object use. Most of the items are answered by identifying a frequency of *not yet*, *sometimes*, or *often*. Five items require the identification of a number. For example, the choices for "How many words does your child use meaningfully that you recognize (such as *baba* for *bottle*; *gaggie* for *doggie*)?" are none, 1–3, 4–10, 11–30, and over 30.

Karen Pierce and colleagues at the University of California San Diego Autism Center for Excellence have been using the ITC as the screening tool recommended in their research with physicians in the greater San Diego area (Pierce et al., 2011). They worked with 170 pediatricians to recommend the screening of 10,479 infants at the 1-year well-baby checkup using the ITC. They found the positive predictive value of using this screening at age 1 to be .75, which is considered high, and conclude that this screening offers an alternative to focusing on screening baby siblings to study autism prospectively. In their publication describing screening instruments for use by pediatric providers such as nurses, Cangialose and Allen (2014) summarized the similarities across three widely used tools in the table reproduced as Table 2.2.

First Year Inventory (FYI)

The First Year Inventory (FYI) is a 63-item questionnaire that parents complete when their infant is 12 months old to examine risk

TABLE 2.2 Similarities in Select Questions from the M-CHAT, ESAT, and ITC Screening Tools

Behavior	M-CHAT	ESAT	ITC
Joint attention	If you point to an object across the room, does your child look at it?	When are you pointing at something, does your child follow your gaze to see what you are pointing at?	When you look at and point to a toy across the room, does your child look at it?
Eye contact	Does your child look you in the eye for more than a second or two?	Is it easy to make eye contact with your child?	When your child plays with toys, does he or she look at you to see if you are watching?
Response to name	Does your child respond to his or her name when you call?	Does your child react when spoken to, for instance, by looking, listening, smiling, speaking, or babbling?	When you call your child's name does he or she respond by looking or turning toward you?
Spontaneous showing	Does your child ever bring objects over to you to show you something?	Does your child, on his or her own accord, ever bring objects over to show you something?	Does your child pick up objects and give them to you? Does your child show objects to you without giving you the object?
Spontaneous pointing	Does your child ever use his or her index finger to point, to indicate interest in something?	Does your child ever use his or her index finger to point, to indicate interest in something?	Does your child try to get you to notice interesting objects—just to get you to look at the objects, not to get you to do anything with them?
Object play	Can your child play properly with small toys (e.g., cars or blocks) without just mouthing, fiddling, or dropping them?	Can your child play with toys in varied ways (not just fiddling, mouthing, or dropping them)?	Does your child show interest in playing with a variety of objects?
Hypersensitivity to stimuli	Does your child seem oversensitive to noise? (e.g. plugging ears)	Does your child react in a normal way to sensory stimulation, such as coldness, warmth, light, sound, pain, or tickling?	N/A
Social interest	Does your child try to attract your attention to his or her own activity?	When your child is left alone for some time, does he or she try to attract your attention?	When you are not paying attention to your child, does he or she try to get your attention?

Source: From Cangialose, A., & Allen, P. J. (2014, January–February). Screening for autism spectrum disorders in infants before 18 months of age. *Pediatric Nursing*, *40*(1), 35.

for ASD (Reznick, Baranek, Reavis, Watson, & Crais, 2007). Parents report on the frequency of behaviors by indicating if they occur never, seldom, sometimes, or often (Ibanez et al., 2014). Results are determined for eight constructs: social-affective engagement, imitation, expressive communication, social orientation and receptive communication, sensory processing, regulatory patterns, reactivity, and repetitive behavior. The First Year Inventory was completed by 12-month-old infants in North Carolina with a follow-up of 699 children at age 3, and it was determined that the FYI was a promising tool for identifying 12-month-olds at risk for a future diagnosis of autism spectrum disorder (Turner-Brown, Baranek, Reznick, Watson, & Crais, 2012). Nearly half of the children identified with ASD at age 3 met the risk cutoff of the

FYI at age 12 months, which is consistent with the reported proportion of children with ASD who have early onset of observable symptoms (Turner-Brown et al., 2012).

Screening Tool for Autism in Toddlers and Young Children (STAT^{TM})

The STAT is a screening tool developed in 1997 by researchers at Vanderbilt Kennedy Center to be used with young children between 24 and 36 months of age (Stone, Coonrod, Turner, & Pozdol, 2004). There are 12 items in the categories of imitation, play, and communication-requesting and communication-directing attention that are completed during observations of a play interaction. Items are scored as either pass or fail or by the number of requests of directing of attention. The utility of the STAT in community-based settings remains to be determined (Stone et al., 2004).

Social Communication Questionnaire (SCQ)

The SCQ is a parent report measure that contains 40 items designed to screen for pervasive developmental disorders in children ages 4 and older (Berument, Rutter, Lord, Pickles, & Bailey, 1999). There are two versions of the questionnaire: one for children younger than 6 years and another for children older than 6 years. Items are scored as either present or absent in the areas of reciprocal social interaction, language and communication, and repetitive and stereotyped behaviors. Examples include "How much language do you think [child's name] understands if you don't gesture?," "When [child's name] is approaching someone to get her/him to do something or to talk to her/him, does [child's name] smile in greeting?," and "Is [child's name] bothered by minor changes in her/his routine? Or in the way her/his personal things are arranged?" The sensitivity, specificity, and positive predictive values are all high when PDD is compared with other diagnoses (Coonrod & Stone, 2005).

In addition to the published screening measures designed to identify autism spectrum disorder, there are other screening tools that focus on the domains of social-emotional development and communication, or the domains that are delayed in children identified with ASD. Squires, Bricker, and Twombly (2002) have created a screening tool, the *Ages and Stages Questionnaires: Social Emotional*, and report acceptable rates of sensitivity and specificity.

Eight surveys completed by caregivers are designed for specific ages between 3 and 66 months. Items on the questionnaires are scored as occurring (a) most of the time, (b) sometimes, or (c) never or rarely. The categories included in each of the surveys are self-regulation, compliance, communication, adaptive behaviors, autonomy, affect, and interactions with others (Squires et al., 2002). It takes approximately 20 minutes to complete one of the surveys. The authors state that the tool can be used as a one-time screen, but it is most beneficial if it is used as a series of surveys to obtain an understanding of the child's social-emotional development over time. Data to determine cutoff scores were obtained by sampling 3,014 children with ethnic backgrounds taken from the proportions reported in the 2000 U.S. Census and include a group of young children identified with a social-emotional disability (Squires et al., 2002).

In a review of the cultural and linguistic responsiveness of commonly used screening and diagnostic tools for ASD, Harris, Barton and Albert (2014) conclude that, without adaptations, these tools are inadequate for use with the culturally and linguistically diverse groups in the United States. "Understanding how culture influences the recognition and definition of autism spectrum disorders will facilitate cross-cultural adaptations of screening and diagnostic tools" (Grinker, Yeargin-Allsopp, & Boyle, 2011, p. 125).

In a 2015 review of the screening tools for autism spectrum disorders that have been adapted for different cultural and linguistic contexts, the authors found 21 articles of tools adapted to 19 countries and 10 languages for children ages 12 months to 18 years (Soto et al., 2015). More than half focused on screeners for young children, and seven of the studies described adaptations of the Modified Checklist for Autism Toddlers (M-CHAT) for use in Spain, Japan, Mexico, Brazil, Sweden, China, and in the Mediterranean. An Israeli version of the First Year Inventory (Ben-Sasson & Carter, 2013) and a Chinese version of the SCQ are other examples of adapted screening tools. The items were adapted in the following ways: changing wording to avoid misinterpretation of cultural norms, adding specific culturally relevant indicators, adding examples to avoid confusion, and altering the format to align with the response styles of those completing the items (Soto et al., 2015). The authors recommend that screening tools used in clinical, educational, and research settings should be adapted to the specific culture and language.

Garcia-Primo and colleagues (2014) summarized the use of screening in Europe, stating that 18 different screening procedures had been used to date using many of the tools described in this chapter. The authors conclude by stating that the only routine screening procedure is being done in Spain using the M-CHAT and that the ESAT and the Belgian-created Checklist for Early Signs of Developmental Disorders are available for use by professionals but are not used as part of routine practice (Garcia-Primo et al., 2014). They also state that choosing a screening procedure that fits a certain context remains difficult and that raising awareness about the early signs of ASD among parents, physicians, and child care professionals across Europe and evaluating and adopting the use of screening procedures are challenges.

Diagnostic Processes

Diagnostic assessments would be made following the identification from a screening assessment, a recommendation from a pediatrician, or a suggestion from a parent who has concerns. Best practice in assessment includes obtaining information from multiple sources using multiple forms of measurement (Gotham, Bishop, & Lord, 2011; Sandall, Hemmeter, Smith, & McLean, 2005). The assessment process typically includes family input via an interview and observation of child behavior during structured and unstructured activities. The tools described in this chapter are often used as part of the multiple measures included in making a diagnosis. In addition to the results from the diagnostic tools, another component in accurate diagnoses is the clinical judgment of the diagnostician, who is usually a psychologist or psychiatrist with experience working with individuals with autism spectrum disorder (Gotham et al., 2011).

Childhood Autism Rating Scale (CARS)

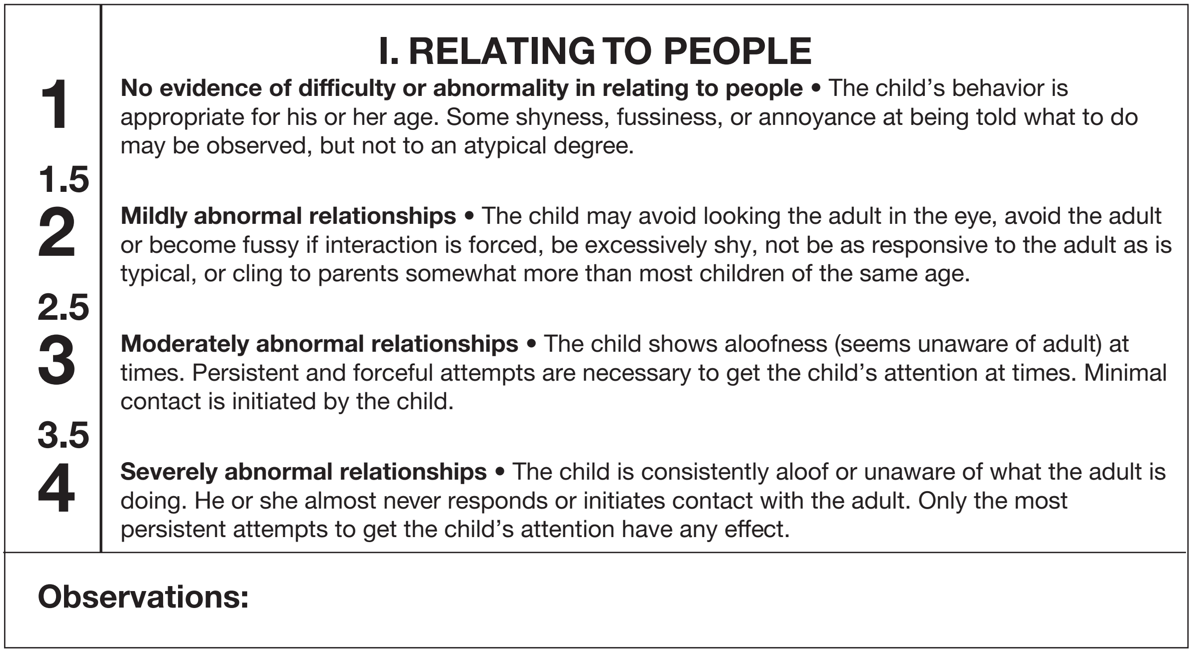
One of the earliest developed and currently most widely used assessment tools is the *Childhood Autism Rating Scale (CARS)* (Schopler, Reichler, & Renner, 1988). The developers of this tool incorporated their 15 years of experience identifying children in the state of North Carolina as part of the Treatment and Education of Autistic and other Communication handicapped CHildren (Division TEACCH) program. The developers evaluated the tool with individuals representing the racial distribution in North Carolina of 67% Caucasian, 30% Black, and 3% other races (Schopler et al., 1988). Items are based on the DSM-IV and 1978 National Society for Autistic Children criteria.

A second edition of the rating scale (CARS2) comprises three instruments (Schopler, Van Bourgondien, Wellman, & Love, 2010). The original scale remains the same and is referred to as the standard version, or CARS2–ST. A second version, or CARS2–HF, also with 15 items, was developed for high-functioning individuals. The standard scale is to be used for individuals under age 6 or over age 6 with an IQ estimated at 79 or lower with impaired communication; the high-functioning version is for individuals age 6 or older with estimated IQs of 80 or above with fluent communication (Schopler et al., 2010). There is also a questionnaire for parents and caregivers (CARS2-QPC). Each of the 15 items is rated on a scale from 1 (within normal limits for the age) to 4 (severely abnormal use of the behavior for age); descriptions of the range of behaviors on the scale accompany each item to assist in the scoring (Schopler et al., 2010). Samples for Relating to People, item 1 from CARS2-ST and item 3 in CARS2-HF, are shown in Figures 2–1 and 2–2.

Considerations for each of the items are found in the CARS2 manual, which is to be used as a guide for the professional administering the scale. It is clear, however, that clinical judgment is required in rating CARS2 items. For example, distinctions between scoring a 3.5 and a 4 require previous knowledge of and experience with individuals with autism spectrum disorders. The authors recommend that the CARS2 be conducted by professionals, including physicians, special educators, school psychologists, speech pathologists, and audiologists practicing with exposure to and training in autism (Schopler et al., 2010). Raw scores are used to categorize the results as nonautistic, autism spectrum—mild to moderate level of behaviors, and autism spectrum—severe level of behaviors.

Gilliam Autism Rating Scale (GARS)

The GARS/GARS2 was designed as one tool to be used by a multidisciplinary team to differentiate those individuals likely to have autism from those who do not (Gilliam, 1995/2005). The scale is designed for completion by a parent, teacher, or caregiver who responds about an individual age 3 through 22 years (Brock et al., 2006). The scale consists of 42 items scored from 0 (never observed) to 3 (frequently observed) and 13 yes-or-no questions regarding the child's development. The items are grouped into four subtests of stereotyped behaviors, communication, social



I. RELATING TO PEOPLE

1	**No evidence of difficulty or abnormality in relating to people** • The child's behavior is appropriate for his or her age. Some shyness, fussiness, or annoyance at being told what to do may be observed, but not to an atypical degree.
1.5	
2	**Mildly abnormal relationships** • The child may avoid looking the adult in the eye, avoid the adult or become fussy if interaction is forced, be excessively shy, not be as responsive to the adult as is typical, or cling to parents somewhat more than most children of the same age.
2.5	
3	**Moderately abnormal relationships** • The child shows aloofness (seems unaware of adult) at times. Persistent and forceful attempts are necessary to get the child's attention at times. Minimal contact is initiated by the child.
3.5	
4	**Severely abnormal relationships** • The child is consistently aloof or unaware of what the adult is doing. He or she almost never responds or initiates contact with the adult. Only the most persistent attempts to get the child's attention have any effect.

Observations:

FIGURE 2–1 Item 1 from CARS2-ST: Relating to people

Source: Schopler, E., Van Bourgondien, M. E., Wellman, G. J., & Love, S. R. Material from the CARS copyright © 2010, by Western Psychological Services. Reprinted by permission of the publisher, Western Psychological Services, 12031 Wilshire Boulevard, Los Angeles, California, 90025, U.S.A. (*www.wpspublish.com*) not to be reprinted in whole or in part for any additional purpose without the expressed, written permission of the publisher. All rights reserved.

3. RELATING TO PEOPLE

This item is related to the first two items, which also rate aspects of social relationships. This item differs in that it is confined to dimensions related to direct interpersonal interactions and the person's expression and reaction to another person. The two dimensions that are rated in this item are the person's initiation of interactions and the reciprocal nature of the interactions.

1	**No evidence of difficulty or abnormality in relating to people** • Age-appropriate initiation of interactions to get help, to have needs met, and for purely social purposes. Interactions with others are fluid and show a reciprocal back-and-forth pattern.
1.5	
2	**Mildly abnormal relationships** • Initiates interactions only to get obvious needs met or around special interests. Some give-and-take noted in interactions, but lacks consistency or fluidity or appropriateness. Aware of other people of same age and interested in interactions, but may have difficulty initiating or managing interactions. Minimal initiation for purely social purposes that does not involve special interests.
2.5	
3	**Moderately abnormal relationships** • Initiates interactions almost totally around his or her special interests, with little attempt to engage others in these interests. Responds to overtures from others, but lacks social give-and-take or responds in ways that are unusual and not always related to original overtures. Unable to maintain an interaction beyond initial overtures.
3.5	
4	**Severely abnormal relationships** • Does not initiate any directed interactions and shows minimal response to overtures from others. Only the most persistent attempts to get the person to engage have any effect.

FIGURE 2–2 Item 3 from CARS2-HF: Relating to people
Source: Schopler, E., Van Bourgondien, M. E., Wellman, G. J., & Love, S. R. Material from the CARS copyright © 2010 by Western Psychological Services. Reprinted by permission of the publisher, Western Psychological Services, 12031 Wilshire Boulevard, Los Angeles, California, 90025, U.S.A. (*www.wpspublish.com*) not to be reprinted in whole or in part for any additional purpose without the expressed, written permission of the publisher. All rights reserved

interaction, and development. Normative data were collected on a sample of 1,092 individuals with autism in the United States and Canada (Gilliam, 1995). Sample items include the following:

Spins objects not designed for spinning
Repeats words or phrases over and over
Uses gestures instead of speech or signs to obtain objects
Non-imitative of other people when playing
Becomes upset when routines are changed (Gilliam, 1995)

Subtest scores above 12 indicate an above average to very high probability of autism, with a reported reliability of between .88 and .96. It is also important to note that the GARS was designed for use with children ages 3 and older, and valid use with younger children is questionable (Coonrod & Stone, 2005). The author states that the GARS can be used to target goals and objectives for students (Gilliam, 1995).

Diagnostic Interview for Social and Communication Disorders (DISCO)

The DISCO (Wing, Leekam, Libby, Gould, & Larcombe, 2002) is a semistructured interview created by authors in the United Kingdom to assist clinicians with the diagnosis and management of individuals with autism spectrum and other developmental disorders (Wing et al., 2002). Information about a broad array of behaviors across domains is collected on the DISCO, including information regarding ratings of current levels of development, degree of delay in milestones, and the severity of atypical behavior. This data can be used to assist with the diagnosis of an individual, and a summary of DISCO ratings provides a detailed database of the percentage of different behaviors that are exhibited by individuals who are classified with autism spectrum disorders (Wing et al., 2002).

Autism Diagnostic Interview–Revised and the Autism Diagnostic Observation Schedule (ADOS)

The combination of the *Autism Diagnostic Interview–Revised (ADI-R)* (Rutter, LeCouteur, & Lord, 2003), a semistructured interview for caregivers, and the *Autism Diagnostic Observation Schedule (ADOS)*, a standardized protocol for observing the communicative and social behavior of toddlers to adults (Lord, Rutter, DiLavore, & Risi, 2001), are considered the gold standard of diagnostic processes (Lord & Corsello, 2005). The ADI-R is composed of 93 items linked to DSM-IV and ICD-10 criteria and takes approximately 2 hours to complete by an experienced interviewer. Clinicians are encouraged to use videos as training materials and it is recommended that clinicians be experienced in working with individuals with autism (Gotham et al., 2011). The questions to be asked of the caregivers for each of the items are clearly marked in a colored box, with the scoring criteria to the right of the text. Inter-rater reliability is reported to be excellent for the domain scores of the three subscales: communication; social reciprocity; and restricted, repetitive behaviors (Chakrabarti & Fombonne, 2001). Researchers evaluated the stability of the ADI-R outcomes when used with children at age 2 to 4 and then again 2 years later and concluded that because domain scores can change over time, the ADI-R should not be used alone for diagnostic purposes (Soke et al., 2011).

The ADOS-2 (Lord, Luyster, Gotham, & Guthrie, 2012) combines the original ADOS designed for children with fluent phrase speech and the Pre-Linguistic Autism Diagnostic Observation Schedule (PL-ADOS) (DiLavore, Lord, & Rutter, 1995) designed for preschool-age children with little expressive language into one instrument (Lord, Corsello, & Grzadzinski, 2014). The ADOS-2 is composed of four modules for use with individuals of varying developmental and language levels. Standardized activities that set the occasion for observation of behavior are recorded on a scale of 0 (regular use or typical behavior) to 3 (lack of skill or behavior). Module 1, Pre-Verbal/Single Words, contains items previously found in the PL-ADOS, module 2 comprises new items designed for individuals with some language, and module 3 contains many of the items from the original ADOS. Module 4 also contains new items that are designed for high-functioning adolescents and adults and includes the added activities of daily living and plans and hopes (Lord et al., 2014). Researchers who used the ADOS module 4 with adult males in four groups—with ASD, with psychopathy, with schizophrenia, and typically developing—confirm that it is a reliable instrument with good predictive value (Batiaansen et al., 2011). Another addition to the ADOS-2 is a module for young children ages 12 to 30 months with minimal language.

The ADOS-2 has been widely used to determine diagnoses for research purposes and to assist in making clinical diagnoses (Lord et al., 2014). The ADOS alone was found to have strong sensitivity and specificity for autism versus not autism and for ASD versus nonspectrum when administered by community clinicians (Corsello, Akshoomoff, & Stahmer, 2013). Researchers have found that the diagnosis for autism remained stable when the ADOS was used with a sample of 82 children from the First Words Project initially at 15 to 24 months of age and then 12 months later (Guthrie, Swineford, Nottke, & Wetherby, 2013).

A 2-day workshop is recommended for training of those who administer the ADOS in clinical settings. Western Psychological Services also produces a guidebook and training videos. Dr. Akshoomoff (In Their Words 2.1) discusses the benefits of the ADOS.

2.1 IN THEIR WORDS

Natacha Akshoomoff,
Ph.D. Associate Professor,
Department of Psychiatry University of California, San Diego

Information Obtained from the ADOS

The *Autism Diagnostic Observation Schedule (ADOS)* has been shown to be a reliable and valid component of the diagnostic process (Lord et al., 2001). The ADOS provides a standardized context in which to assess social interaction, communication, play and imagination, and repetitive behaviors and interests. The administration involves activities designed to press for social and communicative behaviors. The examiner chooses from one of four different modules, based upon the language level of the individual. The provision of separate modules was intended to minimize the potential bias introduced by differences in language ability upon making a diagnostic decision. The revised algorithms for scoring the ADOS now consist of two new domains, Social Affect and Restricted, Repetitive Behaviors, combined to one score, resulting in improved predictive value (Gotham et al., 2011). These revised algorithms also take into account language level and age. Based on the overall sum, the ADOS results in a classification of autism, autism spectrum, or non-spectrum. It is expected that the ADOS will continue to be part of the gold standard for diagnosis using DSM-5 criteria for autism spectrum disorder.

Clinical information provided during ADOS administration can be very useful for program planning. For example, social overtures are broken down into requests, directing another person's attention to something of interest, giving objects to another person, comments, and giving information. This also provides information about the contexts under which the child currently exhibits social overtures. A young child with ASD may respond to bids for joint social attention but may not yet initiate such interactions with others. Basic aspects of social behavior are also closely observed, such as eye contact, facial expressions, use of gestures, vocalizations, and use of objects. Teachers have found it useful to observe the child during ADOS administration. In some cases, the child may exhibit certain behaviors more regularly in this semistructured interaction with an adult that may be less commonly observed in the classroom or when working with familiar adults who provide more support. These differences may provide helpful information regarding the emergence of new skills or a need to focus on generalizing more skills across settings.

A large number of research studies have demonstrated that the ADOS has good inter-rater reliability, test-retest reliability, and diagnostic validity. However, given the short time period provided by the ADOS administration, as well as the fact that it provides an observation only of current functioning, it is important that diagnosis be made not on the basis of the ADOS alone, but rather that the ADOS is used in tandem with parent interview. The test authors originally intended that experienced clinicians would use the ADOS as part of a comprehensive assessment.

The latest version of the DSM-5 (see Chapter 1) includes a rating of severity of symptoms. It is likely that diagnostic tools will need to be developed to reflect this shift from a categorical approach toward a more dimensional framework (Gotham et al., 2011). Along with more refined tools to measure and define severity of ASD, "quantitative approaches to measuring symptoms across domains could improve our ability to describe different developmental trajectories and responses to treatment" (Gotham et al., 2011, p. 39).

Assessments for Educational Planning, Intervention, and Outcomes

Assessments for educational planning can be used by educators and related service personnel such as speech language pathologists. Obtaining relevant information from a psychoeducational assessment depends on making the necessary accommodations and selecting the specific assessments appropriate for use with learners with autism spectrum disorder (Brock et al., 2006). Suggested accommodations and considerations include preparing the student for the experience, placing the assessment session in the student's daily schedule, minimizing distraction, using preestablished physical structures and work systems, using powerful external rewards, carefully preselecting task difficulty, and allowing nonstandard responses (Brock et al., 2006). Autism experts also caution that many assessment instruments have limitations when used with minimally verbal children, or those that have not developed language by age 5, and recommend the development of behavioral measures with benchmarks that accurately reflect the strengths and weaknesses of minimally verbal school-age children with ASD (Kasari, Brady, Lord, & Tager-Flusberg, 2013).

Autism Screening Instrument for Educational Planning (ASIEP-2)

The ASIEP-2 was initially designed to assist public school personnel with identifying individuals with autism (Krug, Arick, & Almond, 1993). The ASIEP-2 is composed of five standardized subtests that can be used for diagnosis, placement, educational program planning, and progress monitoring. Included as part of this instrument is the *Autism Behavior Checklist (ABC)*, which provides 57 items, and teachers and parents circle the responses that describe the focal child. The ABC was intended to be the initial step in educational planning by teachers. Although the ABC has limitations as a screening instrument, it has value in documenting change, especially if the observed behaviors scored decrease in number following educational intervention (Lord & Corsello, 2005).

An Interaction Assessment Record Form is also included to guide observations of children during social interaction and constructive play. A Vocal Behavior Sample and a Prognosis of Learning Rate obtained by recording the child's responses during discrete-trial instruction are two additional subtests. The fifth subtest, typically administered by the teacher, is the Educational Assessment; it is composed of four sections: receptive language, expressive language, body concept, and speech imitation. This subtest provides particularly relevant information that assists with the identification of educational needs (Krug et al., 1993).

Psychoeducational Profile (PEP)

The *Psychoeducational Profile*, currently in the third edition (PEP-3), was designed by the TEACCH program to identify the strengths and weaknesses in skills of individuals with autism spectrum disorders age 6 months through 7 years for the purpose of educational planning (Schopler, Lansing, Reichler, & Marcus, 2005). The normative sample used for comparison of results was taken from 407 individuals with autism spectrum disorders collected from 21 states in the United States. The sample also reflected the U.S. Bureau of Census data with regard to ethnicity, race, income, and level of education (Schopler et al., 2005).

The assessment is to be conducted in two parts. The first, the Caregiver Report, is a new component in this third version of the PEP (Schopler et al., 2005). Caregivers are asked to identify their child's developmental level in several categories and compare this with typical child development. They also report on developmental history, problem behaviors, personal self-care skills, and adaptive behavior skills that include responding to a hug and participation in new activities. Scores from the Caregiver Report can be compared to percentiles from the normative sample found in the examiner's manual (Schopler et al., 2005).

The second component, the Performance Profile, is composed of 10 subtests—six that measure developmental abilities and four focused on maladaptive behaviors (Schopler et al., 2005). An educator can purchase a test kit with all of the materials needed to administer the performance measures. Through a series of test items and activities, the test administrator scores a possible 172 items as 0 (failing), 1 (emerging), or 2 (passing). Administration directions are provided for each item, but the order of administration can be flexible and does not need to be standardized. The six performance subtests scored are cognitive verbal/preverbal, expressive language, receptive language, fine motor, gross motor, and visual-motor imitation. The six performance and four maladaptive subtests—affective expression, social reciprocity, characteristic motor behaviors, and characteristic verbal behaviors—are recorded throughout the presentation of all activities and then summarized into composite scores for communication, motor, and maladaptive behaviors.

Multiple areas are scored during each activity of the PEP-3 on the Examiner Scoring and Summary Booklet. For example, during the activity with items hidden in a denim pouch, the subtests of cognitive verbal/preverbal (CVP), gross motor (GM), affective expression (AE), and characteristic motor behaviors (CMB) are scored. Each of the performance subtests is then summarized separately, and the examiner can identify areas of strength as well as areas of focus for educational planning. Educators can use individual strengths when designing curriculum. Information from the Caregiver Report can be used by educators to address those skills and behaviors reported to occur at home.

TEACCH Transition Assessment Profile (T-TAP)

The T-TAP is a major revision to the *Adolescent and Adult Psychoeducational Profile* that is designed for the purpose of developing individualized treatment goals for adolescents and older individuals with autism spectrum disorders and addresses the transition needs of this age group (Mesibov, Thomas, Chapman, & Schopler, 2007). The tool is composed of a direct observation scale and two interviews that include a home scale and school/work scale. Each scale is composed of six functional areas: functional communication, leisure skills, vocational skills, vocational behavior, interpersonal behavior, and independent functioning (Mesibov et al., 2007). This instrument is one of the few available that can be used to target skills for intervention with adults with autism spectrum disorders (Lord et al., 2014). The T-TAP manual contains sample forms that can be used to support transition planning and forms to record progress with targeted skills.

As part of their book, Quill, Bracken, and Fair (2000) have published the Assessment of Social and Communication Skills for Children with Autism. This assessment tool can be used as a caregiver or teacher interview measure and includes information about the child's play, communication, and social skills observed at home, at school, and in the community. It identifies motivators and describes challenging behavior. The person completing the interview is asked to identify whether any of the skills demonstrated generalize across environments. An assessment summary sheet is included to assist educators with the identification of target objectives. The book (Quill, 2000) contains suggested activities for teaching any of the skills targeted. The activities are designed for younger children.

Vineland Adaptive Behavior Scales

The *Social-Emotional Early Childhood Scales* (*Vineland SEEC*) (Sparrow, Cicchetti, & Balla, 1998) containing a number of items that would be impaired in young children with ASD was designed to be completed in a semistructured interview format with an adult familiar with the child's social-emotional behavior. Responses to items are compared to a standardized sample of young children from birth through 5 years 11 months taken from the national sample obtained for the *Vineland Adaptive Behavior*