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Please enjoy this complimentary excerpt from The Educator's Guide to Autism Spectrum Disorder.

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# An Overview of Autism Spectrum Disorder (ASD)

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## What Is Autism Spectrum Disorder?

In 1943, Leo Kanner first described autism in his article “Autistic Disturbances of Affective Contact.” Previously, most of the individuals who exhibited the symptoms that Kanner described were classified under the diagnosis of schizophrenia or intellectual disabilities (ID). Kanner noted distinct differences in the subjects that he observed with autism than others in the schizophrenia and ID categories: resistance to change, insistence on sameness, echolalia, and without a desire to be social (Kanner, 1943). Unfortunately, his description of these individuals’ preference for being alone, often not showing a desire for affection from their parents, led to some confusing and erroneous viewpoints that the mother’s aloof interactions with their children caused the autism disorder (Kanner, 1943). Hans Asperger also published his dissertation about the disorder of autism in 1944 (but it was not found or translated until 1981) and described it as being inherited from the parents because he found that the fathers of the children seemed to demonstrate similar characteristics. Asperger’s description of autism later was recognized as one that fit a distinct subgroup of individuals within the autism category and thus the label “Asperger’s syndrome” was created and provided to individuals with more advanced expressive language skills and no intellectual delays.

In the 1960s and 70s several researchers, most notably Bernard Rimland and Michael Rutter, made significant gains in clarifying and describing the disorder of autism in order to develop a more accurate means of diagnosis, with the hope of developing effective interventions and treatments for individuals with autism. In 1975 when the first federal special education law was passed, Education for All Handicapped Children Act (PL 94-142) (U.S. Department of Education, 2022), children with autism, along with all other children with disabilities, were granted a right to be educated free in public schools. This also increased the need for further research regarding a consistent diagnostic criteria for autism and effective intervention methods for children with autism (Fine, 1979).

In 1978, Rutter wrote a new definition of autism and in 1980 the third revision of the *Diagnostic and Statistical Manual of Mental Disorders-III (DSM-3)* (American Psychiatric Association [APA], 1980) was published and included the first diagnostic criteria for “infantile autism” under the category of Pervasive Development Disorder. The emphasis was on early childhood characteristics and development. At that time in 1980 autism was considered to be a rare disorder with a prevalence of 3 in 10,000 (Maenner et al., 2021). Currently, the prevalence of autism is considered to be 1 in 44, and is 4 times more common in boys than girls (Maenner et al., 2021).

In 1994, the reauthorization of the federal special education law PL 94-142 occurred and “Autism” was added as one of the federal diagnoses with its own disability category and eligible to receive federal funding for services (the law’s name was also changed to “Individuals with Disabilities Education Act” [IDEA] in 1994). This disorder is characterized by difficulty in social interaction with others; speech, language, and communication impairments (e.g., delayed speech, echolalia); restrictive and repetitive behavior patterns; stereotypic and other self-stimulatory responses; and a variety of aberrant responses to sensory stimuli (Chawarska, et al., 2008). At the same time, however, it is not unusual for individuals with autism to have typical physical growth and development, and some children and youth with ASD have splinter skills and other isolated and unique skills, knowledge, and abilities (Berkell Zager, 1999). Moreover, individuals with autism have a wide range of abilities, ranging from

near- or above-average intellectual and communication abilities to severe cognitive delays and an absence of spoken language (Myles & Simpson, 2003).

The most current definition and diagnostic criteria for ASD comes from the new edition of the *Diagnostic and Statistical Manual of Mental Disorders V (DSM-V)* (May, 2013) and was officially sanctioned for use by the American Psychiatric Association (APA). One of the major changes within the new edition (previous edition was DSM-IV-TR [2000]) was a complete revision of the diagnostic criteria for ASD. The Asperger syndrome diagnostic classification was eliminated along with other specific subtypes of autism and replaced with a continuum of severity. Individuals with severe forms of autism fall at Level 3; Moderate is Level 2; and Mild forms of autism are coded as Level 1. It also added the social (pragmatic) communication disorder (now referred to as SPCD) which focuses on difficulties with the use of verbal and nonverbal communication in social contexts as well as the person demonstrating challenges with the functional use of communication in social relationships in both personal and school or professional environments. It is important to note that SPCD diagnosis criteria does not include anything about the individual demonstrating sensory challenges or restrictive and repetitive behaviors. Thus, it is not the same as the previous Asperger's syndrome diagnosis.

The Autism Spectrum Disorder Diagnostic Criteria of the *DSM-V* (APA, 2013) outlines the different pertinent factors that professionals utilize to determine whether an individual manifests an ASD and then provides a table that delineates the three dimensions of severity in which an individual would be classified. In summary, the diagnosis considers the following: Deficits in at least three subcategories of social communication and social interaction and at least two subcategories of restricted and repetitive behaviors or interests *and* symptoms need to be evident at an early age, symptoms result in significant impairment in current functioning, and symptoms cannot be otherwise explained by other disabling conditions, specifically cognitive impairments. For each of the two deficit areas of social communication and interaction and restrictive and repetitive behaviors, the three classifications of severity essentially fall within the three levels of mild (requiring support), moderate (requiring substantial support), and severe (requiring very substantial support).

**Table 0.1** Severity Levels for ASD

SEVERITY LEVEL	SOCIAL COMMUNICATION	RESTRICTED, REPETITIVE BEHAVIORS
<b>Level 3</b> <b>"Requiring very substantial support"</b>	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when they do, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

SEVERITY LEVEL	SOCIAL COMMUNICATION	RESTRICTED, REPETITIVE BEHAVIORS
<b>Level 2</b> “Requiring substantial support”	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
<b>Level 1</b> “Requiring support”	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

Source. American Psychiatric Association (2013).

It is important to note that there are many professionals, families, and individuals with autism and persons previously identified as having Asperger’s syndrome who do not agree with this new diagnostic criteria (Carmack, 2014; Gamlin, 2017; Giles, 2014; Moloney, 2010; Parsloe & Babrow, 2016). These people who received a diagnosis of Asperger’s syndrome prior to the change in the *DSM* diagnostic criteria and who do not want to change their diagnosis to be one that is now listed in the *DSM-V* do continue to self-label as having Asperger’s syndrome, regardless of the fact that the *DSM-V* no longer includes it as a diagnostic criteria area or disability (Carmack, 2014; Smith & Jones, 2020; Soffer & Argaman-Donas, 2021). Many individuals previously diagnosed with Asperger’s syndrome report feelings of concern and disappointment that Asperger’s syndrome is no longer recognized as a separate disorder because of the sense of identity associated with the Asperger syndrome label (Chambers et al., 2020;

Gamlin, 2017; Giles, 2014). The American Psychiatric Association's decision to move Asperger's into the autism spectrum hinged on the issue of language development; the American Psychiatric Association argued that language impairment is not a "necessary criterion" for diagnosing autism (Adams, 2011). Several disability scholars argue for a reenvisioning of Asperger's not as a medical disorder or disability but rather as a socially constructed mental disorder, if it is a disorder at all (Allred, 2009; Molloy & Vasil, 2002). Rather than seeing Asperger's as a neurological impairment, Allred (2009) and Molloy and Vasil (2002) argued that Asperger's is a "difference." It is not that individuals with Asperger's are impaired; it is that they experience the world differently, and thus, respond differently. No matter the type and amount of disagreement regarding the diagnostic criteria and labels in past *DSMs*, it is critical that individuals with ASD of all levels of functioning receive appropriate intervention for their individual needs.

As mentioned above, SPCD is a new diagnostic criteria in the *DSM-V*. Mandy et al. (2017) expresses the views of many other researchers at this point in time when they state, "It is currently unclear whether SPCD is a valid diagnostic category, because little is known about the characteristics of those who meet its criteria" (p. 1116). There is currently no consistent and clear definition or criteria, nor are there any specific screening and assessment tools to help definitively provide a diagnosis of SPCD (Adams et al., 2020; Mandy et al., 2017; Taylor et al., 2016).

The question of whether SPCD can be meaningfully and consistently distinguished from other disorders and from typical development remains to be answered (e.g., Lord & Bishop, 2015; Norbury, 2014). In particular, a crucial consideration is how SPCD relates to, and can be differentiated from, ASD (Brukner-Wertman et al., 2016; Dolata et al., 2022; Weismer, et al., 2021). Some professionals are still not differentiating in their treatment between children who have a Level 1 (mild) ASD diagnosis and those with an SPCD diagnosis when studying effective interventions for working on social communication skills (Adams et al., 2020).

While there are several research articles published since 2013 that address the need to clarify and validate the new SPCD disorder, no research articles were found that discussed or studied how schools are handling the diagnosis of SPCD as far as eligibility for special education, how assessments are conducted, or who and how services are provided. In an online search of reputable organizations (i.e., Centers for Disease Control [CDC], American Psychological Association [publisher of the *DSM*], and Council for Exceptional Children [CEC]), only the ASHA included information about SPCD. While they do provide a clear definition with symptoms and characteristics, it is not a definition that was found anywhere else. They discuss screening and assessment and diagnosis, but no specific tools and all emphasis is placed on observation of the individual and interviewing people who live and work with the child (ASHA, n.d.). They do make it clear that social communication skills are ones that speech and language pathologists (SLPs) are trained to work with in individuals and that SLPs can provide effective treatment for such individuals in 1:1 or small group settings (ASHA, n.d.). Other psychology, psychiatry, and autism center websites all note that the most important professional to be involved in diagnosis, assessment, and treatment is a SLP.

One common characteristic among all individuals with ASD, no matter the severity of diagnosis, is their uneven pattern of skill development (Burack & Volkmar, 1992; National Research Council, 2001; Roane et al., 2016; Van Meter et al., 1997). For instance, an individual with ASD may display math skills several years beyond their age yet may be unable to use the toilet independently. In this connection individuals who teach and plan skill development programs for learners with ASD, including professionals and parents, typically consider the following skill domains: (a) cognition, (b) learning, (c) social interaction, (d) play, (e) communication, (f) adaptive behavior, (g) behavior, (h) motor, and (i) sensory sensitivities (Atwood, 1998; de Boer, 2018;



Klinger et al., 2021; Koegel et al., 1995; Mauk et al., 1997; Mazurek et al., 2012; Myles & Simpson, 2003; Roane et al., 2016).

The Individuals with Disabilities Education Act (IDEA) of 2004 is the current federal law that regulates providing services and support to children with disabilities within schools, ages 0 to 3 (Part C) and ages 3 to 22 (Part B). The IDEA refers to ASD as “a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child’s educational performance” [Sec. 300.8 (c) (1) (i)]. This federal definition then proceeds to name traits commonly related to the condition: “Other characteristics often associated with autism are engaging in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term autism does not apply if the child’s educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in IDEA” [Sec. 300.8 (c) (1) (ii)].

IDEA also notes that a child who shows the characteristics of ASD after age three could be diagnosed as having ASD if the criteria above are satisfied. This enables a child to receive special education services under this classification if they display signs of ASD after their third birthday. This does not mean that a child who is showing signs of ASD prior to age three should not be diagnosed earlier. In fact, it is important to identify children with ASD as early as possible so that early intervention can occur as soon as possible in the child’s early development years (Estes et al., 2015; Howard et al., 2005; Reichow, 2012; Zwaigenbaum et al., 2021). Research over the decades has overwhelmingly indicated that young children with ASD who receive early and intensive intervention after early diagnosis make statistically significant progress (this means that the research showed that the only reason for the improvement in the child’s skill development was because of the intervention that was provided) and gains in all skill areas if they receive the appropriate and individualized intervention as early as possible (Mazurek et al., 2012; Zwaigenbaum et al., 2021). Many of these children go on to be included for much of their education within the general education environment and pursue postsecondary goals such as attending college or obtaining meaningful jobs.

## Cause

ASD is an extremely complicated disorder and one that has taken and is still taking researchers and professionals a long time to figure out the causes and the diagnostic process. Traditionally (1940s–1990s) ASD was noticed, observed, and diagnosed by professionals simply through the demonstration of characteristics such as repetitive and restrictive behaviors (e.g., not playing with toys or handling objects as designed, doing one thing over and over, rocking, hand flapping, lining things up), delayed communication (e.g., no speech development, echolalia [repeating others’ words] or development of only a few words), and lack of desire to interact with others in typical ways (e.g., lack of eye contact, not wanting to be touched, not noticing other people in the room, not talking or playing with other children) and also challenging behaviors that came with lack of communication and wanting things to be a certain way (e.g., screaming and yelling when a person moved one of their objects, not being able to tell a parent they are thirsty). And there was little to no recognition of the sensory difficulties that most individuals on the spectrum experience (e.g., certain noises, the tactile feel of certain things, lighting, the tasted of certain foods) and how those sensitivities or lack of sensitivities (e.g., lack of pain, lack of reaction to noises, lack of reaction to touch) affect their daily ability to function.

During this time, there was no known cause for “autism.” There was no medical or DNA test, or any other physical or biological “autism” test that was provided to an individual to help definitively identify and diagnose the disorder. As a result, there were unfortunately many harmful theories or myths perpetuated to explain the

cause of the disorder. For example, in the 1940s through the 1960s, it was common to believe that autism was caused by having a “cold” or “refrigerator mother,” meaning that she was not attentive or affectionate enough to her child during their early life and thus the child withdrew into their own world and developed “autism” (Kanner, 1943).

In 1998, a now famous article was published in the *Lancet* by a then-British medical doctor, Andrew Wakefield, that claimed there was a link between the vaccinations that young children received between 18 and 24 months and the development of autism (Wakefield, 1998). He claimed that vaccinations for diseases such as measles, mumps, and rubella were triggering something in the bodies and brains of some children and were causing autism to develop after they received these vaccinations. Immediately, this article caused much controversy and many parents began to refuse to allow their children to be vaccinated. This resulted in a rise of the occurrence of many harmful childhood diseases. Many extensive studies were done by medical professionals after this article was published and these studies proved over and over that there was no link between vaccinations and autism (Bölte et al., 2019; Miller & Reynolds, 2009; van der Linden, 2015). Finally, in February of 2010, Wakefield's study was proven fully fraudulent, his article was completely retracted from the journal, and his medical license was taken away (the Editors of the *Lancet*, 2010). It was then further proven that he was in the process of starting a business venture in which he would profit more than \$40 million for developing and selling his own “safe vaccinations” for children. Unfortunately, to this day, many parents continue to believe that vaccinations can cause autism and refuse to allow their children to be vaccinated or claim that their child developed autism from vaccinations they received.

Perhaps the biggest advance in understanding autism and its origins has been the increase in genetic research and its contribution to ASD's etiology. Three types of studies show that there is clearly a genetic and heritable link in ASD: (Castellani 2020; Gaugler et al., 2014; Geschwind, 2011; National Institute of Health (NIH), 2017).

- twin studies, comparing monozygotic (identical) twins and dizygotic (fraternal) twins,
- family studies comparing the rate of autism in first-degree relatives of affected probands versus the population, and
- studies of rare genetic syndromes with a comorbid autism diagnosis.

In 2019, a global research project (50 centers around the world) looking into the possible genetic causes for autism was completed. They reported that there are definitively 102 genes associated with ASD (Satterstrom et al., 2020). The researchers found that the majority of these ASD risk genes are active early in brain development and play a part in controlling the expression of other genes or the communication between brain cells (synapses) (Satterstrom et al., 2020). Additionally, both “excitatory” neurons (increase the likelihood that the neuron will fire an action) and “inhibitory” neurons (decrease the likelihood that the neuron will fire an action) can express the risk genes (nerve cells). This demonstrates that autism involves “multiple abnormalities” in how brain cells work rather than only being linked to one main type of brain cell (Satterstrom et al., 2020). To fully comprehend what each of these genes does, more study is required. The implications for identifying specific genes means that it could be possible for medications or medical treatments to be developed and used with individuals with autism, in addition to or instead of behavioral interventions.

## Diagnostic Process

Because there is not one known cause for autism and not one single test to determine the existence of autism within an individual, it is important for teachers and parents to understand how the autism diagnostic process occurs. Starting in the early 2000s, professionals began developing and researching assessment tools that could be used to determine if an individual could be diagnosed with an ASD. The goal was, and continues to be, to help standardize the process so that there is objectivity and consistency across and among professionals when an ASD diagnosis is provided (Pringle et al., 2012; Volkmar et al., 2014). There has also been the development of several screening tools to help professionals and parents determine if an individual is at risk for ASD. These tools are frequently used to detect characteristics in very young children (as young as 6 months up to 3 years old) so that people can be alerted and begin closer monitoring of the child's development.

The diagnostic process is neither simple nor quick. It requires that professionals who have experience working with individuals with ASD and experience using the assessment tools implement the assessment process. A positive diagnosis of ASD also requires a comprehensive assessment, using several different tools that evaluate the different aspects and characteristics that are common deficits in individuals with ASD. A parent or teacher should be wary of a diagnosis that has been provided to an individual by a professional that has only utilized their "professional expertise" to provide the diagnosis. The best process is for a team of individuals, with different expertise and experience in working with individuals with ASD such as Speech and Language Pathologists, Occupational Therapists, Psychologist or School Psychologists, and Board Certified Behavior Analysts, to work together providing assessments related to their field. Then the team discusses the results across the assessments and across their areas of expertise to determine if they reach the same conclusions regarding the diagnosis or non-diagnosis of ASD. Finally, for the purpose of providing the rationale for giving or not giving a ASD diagnosis, these professionals can either write one comprehensive report, which would combine all of the results, or individual reports with the results of the specific assessments each one administered.

To help teachers and parents understand more about the screening and assessment process that occurs regarding the diagnosis of ASD, a list with corresponding brief descriptions has been provided below regarding the most commonly used, as well as evidence-based screening and diagnostic tools used.

## Developmental Screening Tools

*The Modified Checklist for Autism in Toddlers—Revised with Follow-Up (M-CHAT-R/F)* (Robins, et al., 2009) can be administered and scored as part of a well-child care visit, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT-R is to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk will be diagnosed with ASD. To address this, the Follow-Up Questions (M-CHAT-R/F) were developed. Users should be aware that even with the follow-up, a significant number of the children who screen positive on the M-CHAT-R will not be diagnosed with ASD. However, these children are at high risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who screens positive (for ages 16 to 30 months).



*The Battelle Developmental Inventory—Third Edition (BDI-3)* (Newborg, 2020) is an assessment that measures global domains across the early development years of children. The BDI-3 provides examiners with a complete assessment, a screening assessment, and an early academic survey. BDI-3 is used across the country—and exclusively in 16 states—to (1) assess developmental milestones for school readiness, (2) help determine eligibility for special education services, and (3) assist in the development of IEPs (for ages Birth to 7 years, 11 months).

*The Ages & Stages Questionnaires—Third Edition (ASQ-3)* (Squires & Bricker, 2009) is a developmental screening tool designed for use by early educators and health care professionals. Its success lies in its parent-centric approach and inherent ease of use—a combination that has made it one of the most widely used developmental screeners across the globe. It relies on parents as experts, is easy to use, is family friendly, and creates the snapshot needed to catch delays and celebrate milestones (for ages birth to 5 years, 6 months).

*The Ages & Stages Questionnaires—Social-Emotional—Second Edition (ASQ:SE-2)* (Squires et al., 2015) is modeled after the ASQ-3 and is tailored to identify and exclusively screen social and emotional behaviors. ASQ:SE-2 is an easy-to-use tool; it is parent completed, photocopiable, and culturally sensitive. With questionnaire results, professionals can quickly recognize young children at risk for social or emotional difficulties, identify behaviors of concern to caregivers, and identify any need for further assessment (for ages 1 to 72 months).

*The Social Communication Questionnaire (SCQ)* (Rutter et al., 2003a) brief instrument helps evaluate communication skills and social functioning in children who may have ASD. Completed by a parent, adult, or other primary caregiver in less than 10 minutes, the SCQ is a cost-effective way to determine whether an individual should be referred for a complete diagnostic evaluation. It is available in two forms—Lifetime and Current—each composed of just 40 yes/no questions. Both forms can be given directly to the parent, who can answer the questions without supervision (for ages 4 years and older—mental age of 2+).

*The Social Responsiveness Scale—Second Edition (SRS-2)* (Constantino, 2012) is used as both a screener and a diagnostic tool. The SRS-2 identifies social impairment associated with ASD and quantifies its severity. It's sensitive enough to detect subtle symptoms, yet specific enough to differentiate clinical groups, both within the autism spectrum and between ASD and other disorders. The SRS-2 asks teachers, parents, and others to rate symptoms that they've noticed—at home, in the classroom, or elsewhere—over time. Raters evaluate symptoms using a quantitative scale representing a range of severity. There are Preschool (ages 2.5 to 4.5 years) and School-Age forms (ages 4.0 to 18 years) with Teacher and Parent/Caregiver versions and Adult forms (ages 19 years and older) with Self-Report and Relative/Other Adult versions.

## Components of Comprehensive Assessment for Diagnosis

*The Autism Diagnostic Observation Schedule—Second Edition (ADOS-2)* (Lord et al., 2012b), which also has a Toddler Module version (Lord et al., 2012a), is an activity-based assessment administered by trained clinicians to evaluate communication skills, social interaction, and imaginative use of materials in individuals who are suspected to have ASD. The ADOS-2 was developed to provide an opportunity to observe symptoms and behaviors associated with ASD in a consistent manner across different clients, clinicians, and locations. The ADOS-2 is currently considered the “gold standard” and a necessary component in the assessment of ASD (for ages 12 months to 90 years).

*The Autism Diagnostic Interview—Revised (ADI-R)* (Rutter et al., 2003b) has been used in research for decades. This comprehensive interview provides a thorough

assessment of individuals suspected of having autism. The ADI-R has proven highly useful for formal diagnosis as well as treatment and educational planning. To administer the ADI-R, an experienced clinical interviewer questions a parent or caretaker who is familiar with the developmental history and current behavior of the individual being evaluated. The interview can be used to assess both children and adults, as long as their mental age is above 2 years, 0 months.

*The Developmental Neuropsychological Assessment—Second Edition (NEPSY-II)* (Korkman et al., 2007) combined with quantifiable behavioral observations analysis during assessment and observations analysis from home and school help clarify the nature of a child's skill deficits and provide a basis for developing appropriate intervention recommendations. It enables the evaluator to assess executive functioning/attention, language, memory/learning, sensorimotor functioning, visuospatial processing, social perception, vary the number of subtests according to the needs of the child, obtain a comprehensive view of quantitative and qualitative patterns of neuropsychological performance, facilitate recommendations for mental health interventions, and link results to educational difficulties (for ages 3 to 16 years).

*The Behavior Rating Inventory of Executive Functions—Second Edition (BRIEF-2)* and *Preschool Version (BRIEF-P)* (Gioia et al., 2017) give the information needed to help children and adolescents with executive dysfunction. It digs deeper than similar measures and pinpoints exactly where and why children struggle, so therapists and schools can make informed and impactful intervention and accommodation recommendations. Three domains evaluate cognitive, behavioral, and emotional regulation, and a Global Executive Composite score provides an overall snapshot of executive functioning. It includes 10 clinical scales: Inhibit, Self-Monitor, Shift, Emotional Control, Working Memory, and Plan/Organize which are included on all forms. Initiate, Task-Monitor, and Organization of Materials are also on the Parent and Teacher forms. The Self-Report Form also includes Task Completion. The inventory includes optional ADHD and ASD scoring profiles to use if a professional is utilizing the tool as part of a diagnostic assessment (BRIEF-P for ages 3 to 5.11 years; BRIEF-2 for ages 5 to 18 years).

*The Comprehensive Executive Function Inventory (CEFI)* (Naglieri & Goldstein, 2017) is a comprehensive behavior rating scale of executive-functioning strengths and weaknesses. Completed in just 15 minutes, the CEFI is a versatile instrument that offers information that can be used to guide assessment, diagnosis, and intervention for children and adolescents. In addition to clinical use, it is also useful in research settings because it can effectively measure the success of intervention programs (for ages 5 to 18 years).

*The Vineland Adaptive Behavior Scales—Third Edition* (Sparrow et al., 2016) is an instrument used for supporting the diagnosis of intellectual and developmental disabilities (IDD), as well as for qualification for special programs, progress reporting, program and treatment planning, and research. The Vineland provides corresponding scales to the three broad domains of adaptive functioning specified by the American Association on Intellectual and Developmental Disabilities and by *DSM-5*—communication, daily living skills, and socialization (for ages birth to 90 years).

*The Behavior Assessment System for Children—Third Edition (BASC-3)* (Reynolds & Kamphaus, 2015) is an individually administered, norm-referenced, comprehensive set of rating scales and forms designed to inform understanding of the behaviors and emotions of children and adolescents. Forms available in this system include Parent Rating Scales (PRS), Teacher Rating Scales (TRS), the Self-Report of Personality (starting at 6 years), Student Observation System (SOS), the Structured Developmental History (SDH), and new to the BASC-3, a Parenting Relationship Questionnaire (PRQ). The TRS, PRS, and SOS measure the child's behavior patterns in home, community, and school settings. The SRP can be used to assess the child's thoughts and feelings. The SDH is useful for obtaining students' comprehensive history and background information across social, psychological,

developmental, educational, and medical domains. (There are three separate versions/forms: Preschool: ages 2 to 5 years; Child: ages 6 to 11 years; Adolescent: ages 12 to 21 years.)

*The Adaptive Behavior Assessment System—Third Edition (ABAS-3)* (Harrison & Oakland, 2015) is a rating scale useful for assessing skills of daily living in individuals with developmental delays, ASD, intellectual disability, learning disabilities, neuropsychological disorders, and sensory or physical impairments. Rating forms are filled out by the parent and a teacher. There is also an adult self-rating form. The ABAS-3 covers three broad domains: conceptual, social, and practical, using 11 skill areas within these domains (for ages Birth to 89 years).

A *Functional Behavior Assessment (FBA)* is conducted if the child or adolescent is also exhibiting maladaptive behaviors that are impeding overall daily functioning for self and/or family or impeding learning and functioning within a class environment. The FBA is conducted to determine the function of the behavior through an analysis of setting events, antecedent, behavior, and consequences (ABC). This assists the diagnostic process through providing a more in-depth view of the individual's behavior and root causes.

## History of Interventions and Treatments

It is helpful for educators to understand the history of interventions and treatments for individuals with ASD because it is a short history, a controversial history, and one in which we are still in the making of history. Understanding the history of interventions and treatments of individuals with ASD also helps educators understand how we have come to this current place and time in which it is still critical to do research and publish articles and books about what are and are not EBPs for working with students with ASD.

It is common knowledge that children and adults with disabilities have historically not been treated well in American society and that the rights of these individuals continually need to be advocated and fought for. As previously stated, it wasn't until 1975 that this country gave children with disabilities the right to be educated in public schools. Another right that individuals with disabilities (and also mental disorders) have not had until more recently (within the past 20 years or so) is the right to not be treated with physically aversive methods as a means of punishing their undesirable behaviors.

Even in the early stages of using ABA interventions and treatments, researchers, and clinicians used physically aversive methods to decrease stereotypical behavior (self-stimulation), self-injurious behavior (SIB), destructive behaviors, and aggressive behaviors. While reinforcement for appropriate behavior has always been a part of the intervention methods within ABA, a more preventative and proactive approach to decreasing target problem behaviors has only been emphasized since the early 2000s when Positive Behavior Intervention Supports (PBIS) were researched and found to be more effective than a reactive approach to decreasing inappropriate behaviors.

Back in the 1970s and 1980s, main techniques for decreasing problem behaviors, using the principles of ABA that were used with varying, and sometimes contradictory, reports of success, were differential reinforcement of other or incompatible behavior (DRO/DRI) (Frankel et al., 1976; Homer & Peterson, 1980; Tarpley & Schroeder, 1979), extinction (Jones et al., 1974; Lovaas & Simmons, 1969; Myers, 1975), time-out (Duker, 1975; Harris & Romanczyk, 1976; Measel & Alfieri, 1976), and sensory extinction (Rincover & Devaney, 1982). These are still effective consequence intervention methods, but now Antecedent-Based Interventions (ABI) are the focus of ABA interventions and treatments.

During the same time the only treatments that were reported to consistently have an effect in reducing SIB to clinically acceptable levels were based on the presentation of an aversive punisher contingent upon the demonstration

of SIB, noncompliance, destruction, or aggression. Corte et al. (1971) found that response-contingent electric shock was more effective than DRO or extinction in suppressing SIB. Electric shock was also used to suppress the behaviors of climbing on furniture (Risley, 1968), for incorrect picture identification (Kircher et al., 1971), and failure to come when called (Lovaas et al., 1965; Sajwaj et al., 1974). Lemon juice was put on the lips of an infant as an aversive punisher to decrease life-threatening rumination (regurgitating and chewing food) and presenting an open jar of ammonia under the nose of individuals contingent upon the occurrence of SIB was found to reduce SIB (Altman et al., 1978; Tanner & Zeiler, 1975). Barrett et al. (1981) reported the overall superiority of punishment procedures to the use of differential reinforcement of appropriate behaviors in suppressing stereotypic behavior in two children with mental retardation and autism. Visual screening (putting a cloth on the face of the individual) was used as a punisher for finger sucking with one subject, and tongue depression was used to punish tongue protrusion in the other subject (Bailey et al., 1983). Many of the same aversive punishers were used by educators in special education classrooms (Barton et al., 1983; Kazdin, 1975; McGinnis et al., 1985; Zabel et al., 1985).

Despite the reported successes of these procedures, several issues and protestations by families and professionals continued to arise when the “need” and proposal for using aversive stimulation was discussed. The use of response-contingent electric shock was controversial even in the 1970s and 1980s (Lichstein & Schreibman, 1976). Excessive or improper use of lemon juice can cause permanent damage to an individual’s tooth enamel and repeated applications of lemon juice to a person’s mouth could result in serious irritation to the mouth and lips. Ammonia, if used excessively or improperly, can result in serious burns on the face. Proponents of using these punishers did caution that they should only be used as the proverbial last resort and then only in highly controlled situations (Bailey et al., 1983). However, the use of highly aversive techniques or the reliance upon laboratory-like environments was continually proven to not generalize to more natural environments or situations (Stokes & Baer, 1977).

In 1988, an important article was published by a group of behavior analysts/researchers. It was titled “The Right to Effective Behavioral Treatment” (Van Houten et al., 1988). These behavior analysts provided and explained six tenements that should be rights of individuals with disabilities and the foundation of behavioral treatments and services for individuals with disabilities. An individual has a right to the following:

1. a therapeutic environment,
2. services whose overriding goal is personal welfare,
3. treatment by a competent behavior analyst,
4. programs that teach functional skills,
5. behavioral assessment and ongoing evaluation, and
6. the most effective treatment procedures available (Van Houten et al., 1988).

These rights became foundational components of the policies and procedures and ethical guidelines when the Behavior Analyst Certification Board® (BACB) was formed as a nonprofit organization in 1998 (see more information below in History of Applied Behavior Analysis).

By the 1990s and 2000s, many professionals and families were advocating for strict and ethical guidelines regarding the use of aversive punishers and consequences or reactive-based interventions over antecedent-preventative interventions. In 1999, the BACB published the first set of policies and procedures to ensure that behavior analysts implemented legal, confidential, respectful, and safe treatment for individuals with disabilities. It was titled the “Professional Disciplinary and Ethical



Standards.” Over the years as new research and studies were conducted regarding intervention methods and the implementation of ABA procedures and practices, the BACB continued to modify and expand the standards and they became guidelines for behavior analysts (BACB, 2019). Eventually, and as is the case today, the guidelines became an actual code by which all applicants and certificants are required to adhere: “Ethics Code for Behavior Analysts.” The current version at the date of publication of this book is 2020 which became effective in January 2022 and is available on the BACB website (BACB, 2020).

### History of Applied Behavior Analysis (ABA) as Treatment

In the late 1800s and early 1900s, John Watson, a professor of psychology, presented a paper to colleagues at a conference, proposing a different viewpoint regarding human behavior. He proposed that it is possible to study behavior, take data on what a person is doing, figure out the reasons why (function or purpose of the behavior), and predict and change that person's behavior. This was the genesis of behaviorism and the science of behavior. He drew on Ivan Pavlov's research on reinforcement as a means of increasing certain behaviors that otherwise would not have increased, if not for the reinforcement occurring directly after the behavior (“John Watson and Behaviorism,” 2014).

Many scientists followed Watson's research and principals and conducted their own research. The science of behavior analysis developed and experimental behavior analysis became a specific area of study—clinical research conducted within laboratory settings studying how changes made prior to and after a specific behavior can change that behavior either increasing or decreasing its future occurrence. Finally, Baer et al. (1968) published the seminal article, “Some Current Dimensions of Applied Behavior Analysis,” in the first publication of the peer-reviewed *Journal of Applied Behavior Analysis* which was considered to be the official birth of ABA. ABA as a science involves changing the environment (antecedents and consequences) while working in learning settings (home, clinics, school, community) with individuals in order to make lasting and meaningful changes in their and their family's lives.

It was not until the 1980s and the publication of the article “Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children” by Ivar Lovaas (1987) that the use of ABA with individuals with ASD was studied and researched. He demonstrated that 40 hours a week of an ABA-only intervention compared to 10 hours a week of an eclectic model of intervention produces statistically significant, meaningful, and life-altering improvements in young children with ASD. McEachin et al. (1993) conducted a follow-up study on the same children who received the 40-hour-a-week ABA intervention and all but one of the children maintained their level of skills and functioning. To this day, behavior analysts continue to successfully replicate similar types of ABA-based intensive early interventions with children with ASD and continue to demonstrate its significant effectiveness.

In 1998, due to the increase in demand for behavior interventionists to create and implement ABA-intensive early intervention programs, the BACB was established as a regulatory entity “to meet professional certification needs identified by behavior analysts, governments, and consumers of behavior-analytic services. The BACB's mission is to protect consumers of behavior-analytic services by systematically establishing, promoting, and disseminating professional standards of practice” (BACB, 2022a). In 1999, the first 28 professionals became BCBAs and today (as of July 2022) there are 56,691 BCBAs (not including the Board Certified Assistant Behavior Analysts (BCaBA) and Registered Behavior Technicians (RBT) (BACB, 2022b). The certification includes the use of ABA practices in general with any population and is not specific to ASD. Of all BCBAs and BCBA-Ds (behavior analysts



with doctorate degrees in behavior analysis) who responded to a survey in January 2022, 71.4 percent work in the field of ASD (BACB, 2022b).

Up until the year 2000, most parents and families across the nation had to pay all costs and expenses for implementing ABA early intervention intensive programs implemented within the home or a private clinic or school. These costs ranged around \$40,000 a year. In 2001, Indiana was the first state to pass a law that mandated health insurance to cover the costs of ABA services for children with autism. As of 2019, all 50 states have mandated insurance coverage for ABA services for individuals with autism outside of the 5- to 22-year age range in which public schools are required to provide services for children with disabilities through IDEA. In 2004, with the reauthorization of IDEA, and the mandate that scientifically based interventions be used in schools for children with disabilities, many mediation and due process hearings, in which parents request ABA services be implemented in the school setting, have been upheld.

In the past decade, professional organizations that support behavior analysts and are governed by behavior analysts have produced and published documents for professionals and parents to help clarify what ABA is, the evidence base of ABA interventions, how to identify ABA interventions, EBPs for individuals with autism, how ABA interventions should be implemented with individuals with ASD, and the experience, education and certification requirements of people practicing as behavior analysts. In 2005 the first notable publication, summarizing and providing factual information regarding the majority of interventions and treatments that were available for use with individuals with ASD was a book by Simpson et al. (2005) titled *Autism Spectrum Disorder: Interventions and Treatments for Children and Youth*. The purpose of the book was to help families and professionals working with children with autism understand, from an objective point of view, what the interventions and treatment were, the risks and costs of use, what research and evidence there was or was not for the use of these interventions, what training and qualifications were needed to implement the intervention, and finally a rating that placed the intervention or treatment into a category indicating the evidence base and effectiveness of the intervention.

Since then, several other publications came out using similar rating scales to classify the different interventions and treatments that are available and being used with individuals with ASD. We provide further information about these reviews in the next chapter, Evidence-Based Practices, and incorporate the information from these reports within the different chapters on interventions and treatments.

In 2012, the first edition of “Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers” was created by the BACB and revised in 2014. This set of “guidelines are intended to be a resource for healthcare funders and managers, regulatory bodies, consumers, service providers, employers, and other stakeholders” (CASP, 2020) regarding the implementation of ABA intervention with individuals with ASD. In 2016 and again with an update in 2017, the Association for Professional Behavior Analysts (APBA) issued a white paper titled *Identifying Applied Behavior Analysis Interventions* (APBA, 2017) to “dispel some of the most common misconceptions about behavior analysis and to help consumers, members of various professions, funders, and policymakers differentiate ABA interventions from others. It presents key facts about the defining features of the discipline with supporting documentation” (APBA, 2017, p. 4). In 2019, APBA, in collaboration with the BACB, posted a white paper on *Clarifications: ASD Practice Guidelines* to update the 2014 guidelines and “to assist payers and providers by clarifying and amplifying the Guidelines that pertain to the intensity of treatment, the intensity of case supervision, and caregiver training” (APBA, 2019, p.3) regarding ABA interventions for individuals with ASD. All of these documents are easy to read and are very helpful for educators to utilize as guidelines for their own practice in schools.

These documents are also helpful for educators to provide to other professionals and parents and family members with whom they work.

## Co-Occurring Conditions

Comorbidity refers to the presence of two or more mental health conditions, disorders, or disabilities. Many individuals with ASD have comorbid conditions in addition to their ASD diagnosis. Many professionals, and particularly those in the medical field, use the terminology *comorbidity*. However, we will use the term *co-occurring* to represent a strengths-based, educational approach rather than a medical approach. Special education teachers and other related school professionals (e.g., general education teachers, counselors, administrators) must support the complex needs of students with ASD, including those needs that manifest as a result of a co-occurring condition. Sometimes it can be difficult to determine if a student's behavior is a manifestation of ASD or another condition or disorder. Distinguishing ASD characteristics from other characteristics is important for not only diagnostic purposes but treatment as well (Mannion, & Leader, 2013; Ung et al., 2013). Therefore, it is advantageous for school professionals to develop awareness and knowledge related to common co-occurring conditions of individuals with ASD. It is also highly likely that school professionals will work with students with ASD and co-occurring conditions.

In addition, characteristics associated with ASD are related to the mental health and overall well-being of the individual with ASD. For example, students with ASD are unfortunately vulnerable to being teased or bullied due to characteristics associated with the disorder (e.g., challenges with social and communication skills, repetitive patterns of behavior). Students with higher levels of bullying in their lives are more vulnerable to anxiety and depression (Chou et al., 2020). Teachers who work with students with ASD must support the entire student, not one discrete area of need. In the section below, we review some common co-occurring conditions with ASD.

Please note teachers do not diagnose ASD or any other mental health condition, disorder, or other disability. Rather, students and their families typically receive diagnostic information from a medical doctor, pediatrician, or assessment clinic and then bring that information to the school. The school team reviews all available medical information as part of the referral process to determine the student's eligibility for special education services. The student will then receive an educational diagnosis following one of the 13 disability categories as described by IDEA (2004). Students with ASD typically receive special education services under the "Educational Autism" disability category (IDEA, 2004). However, they may also receive services under the "Intellectual Disability," "Other Health Impairment," or other disability category determined most appropriate by the IEP team. It is the responsibility of the IEP team to determine which disability category is most appropriate for a student to receive special education services.

## Mental Health

The prevalence of school-age students with ASD and co-occurring mental health conditions is high. The specific prevalence varies according to different sources but anxiety and depression are particularly prominent. A meta-analysis found approximately 40 percent of children and adolescents with ASD have at least one type of anxiety disorder such as excessive worry, the need for reassurance, the inability to unwind, and feelings of self-consciousness (van Steensel et al., 2011). The two illnesses can be distinguished from one another, however, by the pronounced social and communicative impairments present in ASD but absent in anxiety disorders, as well as the developed social insight seen in children with anxiety disorders but absent in ASD (Hollocks et al., 2019; Kim et al., 2000).

Children, adolescents, and adults with ASD are also more likely to have depression compared to individuals without ASD (Hudson et al., 2019). Specifically, individuals with ASD are four times more likely to experience depression at some point in their lifespan. There are varying reports of prevalence rates, which can be attributed to a variety of factors such as a lack of validated instruments for measuring co-occurring psychiatric disorders (DeFilippis, 2018). Areas of concern related to co-occurring ASD and depression are vast and include potentially being at risk for suicide and overall higher levels of care (Pezzimenti et al., 2019).

In addition to depression, generalized anxiety, social anxiety, specific phobias, and obsessive compulsive disorder, are also common. Youth with ASD have a higher prevalence of social anxiety than the general population (Vasa & Mazurek, 2015). Higher levels of autism-specific characteristics have been associated with higher levels of social anxiety (Hallett et al., 2010; Min Liew et al., 2015). In particular, the overall social competence of an individual affects their autistic characteristics and social anxiety (Min Liew et al., 2015). Students with co-occurring ASD and social anxiety may receive both educational and medical treatments. In regard to OCD, this disorder has a later onset than ASD, is marked by ego dystonic repetitive patterns of behavior, and is not often linked to social or communicative difficulties (APA, 2013).

## Intellectual Disability

The key characteristics of intellectual disability include impairments in cognitive abilities and everyday life or adaptive functioning skills (APA, 2013). These characteristics appear during a child's developmental period, vary in severity, and last throughout an individual's lifetime. Cognitive abilities are typically measured through standardized intellectual quotient (IQ) tests such as Wechsler Intelligence Scale for Children—Fifth Edition (WISC-V; Wechsler, 2014). ID is considered two standard deviations or below the general population, which would be an IQ score of approximately 70 or below (APA, 2013).

ID is one of the most common co-occurring disorders with ASD. Prevalence rates vary from an estimated 30 to 70 percent of individuals with ASD reported as having an ID (Fombonne, 2009; Matson & Shoemaker, 2009; Schofield et al., 2019). Individuals with co-occurring ASD and ID have unique needs compared to individuals with ASD alone. For instance, youth with ASD and ID experience more psychological and social difficulties compared to youth without disabilities and youth with ID alone (Baker & Blacher, 2021). Examples of such social difficulties include internalizing behavior, problems with developing friendships, and peer acceptance. Similarly, youth with ASD and ID are at risk for overall lower quality of life in important areas such as social inclusion and well-being (Arias et al., 2018). Teachers who work with students with co-occurring ASD and ID will need to support all of their areas of needs and particularly cognitive skills and adaptive functioning.

## Seizure Disorders

One of the things that can be difficult for educators working with children with ASD is that they have a higher prevalence of seizure disorder or epilepsy compared with the general population (Capal et al., 2020; Viscidi et al., 2014). Epilepsy commonly occurs in individuals with ASD with a prevalence ranging from 2.4 percent to 46 percent vs 0.4% to 0.8% in the general population (Capal, 2020; Strasser et al., 2018). Conversely, rates of comorbid ASD in individuals with epilepsy are also higher, suggesting a common neurodevelopmental pathway (Capal et al., 2020).

Epilepsy is a disorder in and of itself that is still not well understood, although a significant amount of research has been conducted to determine the causes of

seizures, the neurological impact of seizures, and medications that can help prevent or help individuals recover from seizures. In about half of the people that have epilepsy, there is no known cause (Mayo Clinic Staff, 2021). Epilepsy is a serious medical disorder and the occurrence of seizures can occur at any time and without warning. Educators need training in handling seizures and remaining calm and decisive while attending to an individual during and after a seizure.

Comorbid ASD and epilepsy have been associated with worse adaptive functioning, behavior, and quality of life. In one large cross-sectional study of children with ASD, Viscidi et al. (2014) found that children with both ASD and epilepsy exhibited greater impairment when compared with children with ASD and no epilepsy. They found that this relationship was mostly explained by low IQ. In a separate study comparing children with ASD with and without epilepsy, Turk et al. (2009) found that children with both ASD and epilepsy had more impaired daily living skills, motor skills, and challenging behaviors.

Results of Capal et al.'s (2020) recent exploratory study demonstrated that individuals with ASD, who were followed before they developed a seizure disorder, were found to already be distinct in differences and severity of characteristics from their same-age and same-sex compatriots. This suggests that it is not the seizures or neural activity that are responsible for more severe symptoms. Overall, the clinical impact of seizures on the phenotype (observable characteristics and symptoms) of ASD is still not well understood and researchers continue to investigate the relationship between the two (Capal et al., 2020; El Achkar et al., 2015).

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